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The Mother's Perspective: Understanding More about Health Care Experiences
of the Preschool Child with Autism

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A Dissertation Submitted to the Graduate School of the University of Missouri- St. Louis
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Abstract

Background Information: The prevalence of autism spectrum disorders (ASD) has dramatically risen over the last decades. It is known that children with ASD visit health care providers (HCP) more frequently than typically developing peers. Given behavioral and medical complexities of these children, mothers may experience barriers in this process.

Purpose: The purpose of this study was to gain a better understanding of mothers' experiences of taking their children to the HCP. Aims of this study were to reveal mothers' concerns related to these experiences, examine resources and barriers affecting the quality of the visit, and discover more about the effect of autism on mothering.

Methodology: This interpretive phenomenological study interviewed 11 mothers of preschool age children with a diagnosis of ASD. Interviews were conducted using guides developed by the researcher. Transcripts were analyzed using interpretive sessions, paradigm cases, and thematic analysis.

Data Analysis: Three main themes emerged from the transcripts in this study. These themes included feelings that HCPs do not understand the complexity of caring for a child with ASD, marginalization of mothers by the HCP, and a transformation of the mothering role that occurs during the time from diagnosis to early intervention.

Implications for Practice: The need for the HCP to create child-specific profiles emerged from this study. This profile should include information that will enhance the delivery of health care for the child with ASD. Details and necessary information for the creation of this profile are addressed in this paper.

Acknowledgements

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Dedication

There are many people in my life that I need to thank for supporting me through this journey. To them, I dedicate this work.

First and foremost, thanks to my wonderful husband, John. He has been the love of my life for as long as I can remember. He is my rock and has always supported me in any and many ways. I could not ask for a better best friend and husband. I am so blessed to share my life with him.

Second, many thanks go to my three beautiful daughters, Mandy, Laura and Rachel. They put up with a lot over the years and have been real troopers. They have taught me so much about being a mother and a person. Their bright smiles, wit, fun attitudes and laughter are the bright spots in my day.

Third, thank you to my parents. They made many sacrifices for me and provided so much to me in the way of love, support, and opportunities. My many accomplishments are a result of this.

Lastly, thank you to the many people who helped me finish this work. To my advisors, Dr.'s Bachman, Pohlman, Garzon, and McCathren—I cannot thank you enough for sharing your expertise and time with me. And also thank you to the mothers that shared their stories with me. I have always known of your strength. By sharing your stories, I have become a better mother, person, and nurse.

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Chapter 1: Background

All the many fantasies I have had of Darwin waking up one morning, spontaneously talking, being fully toilet-trained, and no longer being a toddler trapped in the body of a young adult raced through my mind. I thought of how often we have wondered what Darwin would be like if we could just somehow remove the extra chromosome in every cell of his body, magically discover a cure for autism, and rewrite his childhood to eliminate his seizure disorder. I thought of the many times Darwin has done something—whether amusing or athletic or downright bizarre—causing us to wonder just how much of Darwin is *really* Darwin and how much of his personality is shaped by his disability
(Carter, 2004, p. 181)

Introduction

Parenting any child is filled with challenges. The challenge of what each day may bring. But usually, parenting follows a fairly predictable developmental pattern as the child grows. “This too shall pass” is a familiar phrase used to describe the trials and tribulations of the social and cognitive development of most children. However, this is not the case for many parents and children affected by autism. Parenting a child who has an autism spectrum disorder (ASD) is filled with unknowns. The unknown of why this happened, what caused it to happen, and what will happen? Everyday events can present unique challenges for the child with ASD.

This chapter will introduce important background information that supports the need and purpose of this study, to understand more about the health care experiences of the mother of a young child with ASD. The burden of ASD on the parents, the child, and the health care environment is overwhelming (Liptak, Stuart, & Auigner, 2006; Newschaffer & Curran, 2003). An important step toward meeting the health care needs

of this growing population includes understanding more about the health care experiences of these families affected by autism.

Autism Spectrum Disorder

Autism was first described in the 1940s by Dr. Leo Kanner, a psychiatrist. Dr. Kanner presented several case studies of children who demonstrated “fascinating peculiarities” and a condition that differed “markedly and uniquely from anything reported so far” (1943, p.217). These children showed little affection toward their parents, preferred to be alone, and were able to master skills such as patterning and counting at a very early age (Kanner, 1943). Since then, the definition and diagnostic criteria of autism has been refined.

Children with ASD exhibit impairments in social interaction and communication along with restrictive or repetitive patterns of behavior (American Psychiatric Association [APA], 2000; Johnson, Myers, & The Council on Children with Disabilities, 2007). These impairments can range from mild to profound (Newschaffer & Curran, 2003). Over time, the characteristics associated with autism spectrum disorders primarily translate into difficulties for the child in social functioning, such as adapting to novel events and settings. Because of this, routine is extremely important in a child with autism’s life. Any change in that routine can lead to upset. Even simple events, such as regular visits to the health care provider, are capable of producing excessive anxiety leading to negative behaviors and actions in a young child with autism.

Both hyper- and hypo-sensitivity to stimuli, such as sound, touch, and visual overcrowding, are known to increase negative behavioral reactions in the child with ASD

(Marshall, Sheller, Mancl, & Williams, 2008). Some of these negative reactions include yelling, screaming, hitting, and even self-abusive behaviors. It is also typical for children with ASD to put their hands over their ears or even socially withdraw in situations. This is especially true when stimuli become overwhelming to them.

Increasing Prevalence of Autism

The prevalence of autism in 2002 was estimated to be approximately one per 150 children in North America as noted by the Centers for Disease Control and The Council on Children with Disabilities (Centers for Disease Control and Prevention, 2007; Johnson et al., 2007). Most recent epidemiological studies now estimate this prevalence to be one in 110 children, an increase in prevalence of approximately 57% (Centers for Disease Control and Prevention, 2009). Data show that since 1980, these rates have continued to climb at alarming rates (Blaxill, 2004; Fombonne, 2003a; Newschaffer, Falb, & Gurney, 2005). Without a determined cause of ASD and no preventative strategies or cures, the increase in children diagnosed with ASD is not expected to diminish.

As these numbers have continued to rise over the last four decades, health care providers continue to try to understand more about the cause of this disorder. What is known is that evidence shows that males are four times more likely than females to be diagnosed with an ASD (Centers for Disease Control and Prevention, 2009).

Additionally, there is sufficient evidence suggesting an underlying genetic cause of autism (Pickler & Elias, 2009). A sibling predisposition to developing ASD provides more supporting evidence of this genetic link (Nadel & Poss, 2007). The statistics for autism spectrum disorders is frightening to all parents, affected or not by this disorder.

Of an even bigger concern is that there continues to be no validated medical treatment for ASDs.

The Preschool Years, a Time of Social Development

The toddler and preschool years are a time when children develop socially acceptable behavior patterns. This can be extremely difficult when the young child has an ASD. Parents of children with ASD are left with few answers on how to cope with the difficult and unusual behaviors these children often exhibit. More specifically, the preschool years are a time when children start to communicate more effectively while increasing their ability to develop social cues and behaviors (Noonan & McCormick, 2006). Developmentally, preschool children with ASD are not able to keep up with their typically developing peers in the areas of social and behavioral development. As other children are developing and learning about the social context of situations and how to behave, preschool children with ASD struggle in a variety of social environments (Department of Health and Human Services [DHHS], 2008).

Visits to health care providers occur frequently in early childhood and are important due to the need for preventative care as well as restorative care for illnesses. Preschool children are exposed to many respiratory infections and viruses especially when they start school or attend day care. These children are also visiting the health care provider for yearly physical exams and routine immunizations. Health care visits can be difficult for the typically developing preschool child due to fears that are a normal part of their social and cognitive development. However, these fears can be especially

accentuated for the preschool child with ASD. This is due to their atypical social development as well as the change in routine that happens during the health care visit.

Mothering

Mothers have increased involvement in the day-to-day care giving practices and responsibilities of children and especially young children. It is common for a mother to be a major care giver when a child is ill or needs to visit the health care provider (Tsai, Tsai, & Shyu, 2008). This is especially true when it comes to health care visits for children with ASD and other developmental disabilities (Liptak, Stuart, et al., 2006; Sen & Yurtsever, 2007). Therefore, since it is a child's mother that most frequently interacts with the health care provider, it is important for providers to understand the mother's perspective in order to engage and develop an effective relationship with that parent.

Mothering can bring forth great joy -- the joy of knowing that a baby developed within you and that a mother's nurturing and caring help shape and support the baby's development. However, when something is not right and a mother's intuition sets in, that fear and worry can be overwhelming (Wachtel & Carter, 2008). This occurs for mothers whose children were later diagnosed with an ASD. They often sensed things were not quite right and then sought help and looked for answers (Caronna, Augustyn, & Zuckerman, 2007). Frequently, these mothers discuss the concerns with their pediatrician or other health care provider, starting their journey into the world of autism.

Mothers will need the health care provider to listen to their intuitions and provide answers to their questions. Therefore, fostering and developing the relationship between mother and health care provider is important. Discovering more about the relationship

between mother and health care provider can lead to a better understanding of the health care needs of the child with ASD.

Health Care for a Child with ASD

A diagnosis of ASD frequently starts with the child's primary health care provider. Administration of screening tools and developmental questionnaires along with addressing concerns from parents mark the beginning. From there, frequent visits to other health care providers begin. Neurologists and psychiatrists are just some of the specialists that, along with the child's primary care provider, become regular health care providers for a child with autism. It comes as no surprise that this child interfaces with the health care field many times in early childhood (Krauss, Gulley, Sciegaj, & Wells, 2003; Myers, 2009). This is not only for the regular well care from the primary care provider and visits for illness, but also for appointments with neurology or psychiatry for behavior management.

In addition, children with ASD may have coexisting health care needs. These children frequently have other comorbidities that necessitate increased numbers of health care visits to specialists in addition to their primary health care provider. It has been estimated that health care for this population costs three times more than the cost for the typically developing child (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006). These increased health care expenditures are a clear indication that children with ASD are frequent consumers of health care services.

Significance of the Study

Although fathers are involved in childcare, mothers often fulfill a greater role related to childrearing in the typical American family (Duarte, Bordin, Yazigi, & Mooney, 2005; Haussler & Kurtz-Costes, 1998; Sen & Yurtsever, 2007; Tehee, Honan, & Hevey, 2009). Frequently, health care visits become the responsibility of the mother in the early years (Liptak, Stuart et al, 2006). Therefore, mothers both arrange and take the child to the health care visit. Since preschool children with ASD frequently visit the health care provider, and it is known that these children have difficulty with changes in routine and social interactions, the mother of a child with ASD is uniquely situated to describe these health care experiences.

Educational research has clearly described the unique social behaviors exhibited by children with ASD and how these behaviors affect the educational process. These children require modifications to their educational plans due to challenging behaviors, communication deficits, and poor social skills (Ollendick, Weist, Borden, & Greene, 1992; Sansosti, Powell-Smith, & Kincaid, 2004). However, there is scant information in the existing nursing literature regarding both barriers and resources that exist in providing health care to children with ASD. Individual educational plans must be developed to address these children's levels of ability, development, and behaviors in the school setting (Myers, Johnson, & the Council on Children with Disabilities, 2007). Therefore, it is understandable that unique plans may also be necessary for this population when they are in the health care setting.

Characteristic behaviors for children with ASD may include aggressive actions, self-injurious behaviors, and socially inappropriate conduct, such as yelling, screaming, or running away (Noonan & McCormick, 2006). Children with ASD frequently have difficulty generalizing behaviors to new situations and communicating and interacting in a socially acceptable manner (DHHS, 2008). Although it might be assumed that these factors affect the frequency and quality of health care interactions, there is little scientific evidence that addresses this specific issue. It is known, however, that these children are large consumers of health services as well as frequent visitors in the health care system (Croen et al., 2006).

Purpose and Aims of the Study

The purpose of this interpretive phenomenological study is to gain a better understanding of mothers' experiences when they take their preschool age child, with autism, to the health care provider. In addition, the researcher would like to gain a better understanding of mothers of children with autism and how autism affects the mothering experience. Mothers in this study will be asked to describe thoughts and feelings surrounding their child's health care encounter in addition to their experiences of mothering a child with ASD. The specific aims of this study are to:

1. Reveal the mothers' concerns and feelings related to the health care experiences and needs of their preschool age child with ASD.
2. Examine resources and barriers that mothers experience when taking their child to the health care provider and how these affect the visit and the outcome of the visit.

3. Describe, from the mothers' perspective, the behaviors that the preschool child with ASD demonstrates and exhibits during health care visits.
4. Discover how the mothers' personal meanings of self and motherhood, along with understanding their child's uniqueness, shape the mothering and care giving practices of her child with ASD.

Exploring and understanding more about the mothers' experiences of their child's health care visits is critical. Their perspective will provide important insights. In the ever changing face of healthcare for the child with autism, learning more from the perspective of the mothers can increase our understanding of the concerns, feelings, resources, and roadblocks that occur in the delivery of health care for the child. Discovering more about this topic and increasing understanding of these experiences will enable health care providers to better meet the needs of this growing population of health care consumers.

Contextual Definitions

Health Care Visit

A health care visit can be defined in many ways, but will be considered an outpatient visit to a licensed health care provider. This health care provider may include a physician, nurse practitioner, or nurse. The visit may be for the purpose of well care, sick care, or follow-up care. Follow-up care may include visits related to the treatment of the child's autism or for a coexisting medical diagnosis. Therapy visits or visits for counseling will not be considered health care visits as these visits are targeted toward treating the behavioral, social, and cognitive deficits of ASD. A focus of this study is to

understand more about the experiences of mothers during the health care visit; therefore, therapy or counseling visits would not apply. Emergency room or urgent care visits will also not be considered as part of the definition of a health care visit for this study. The uncontrolled nature of these visits is sometimes tragic and certainly not routine or regular.

Preschool Age Child

Children's ages are typically categorized into several age groups based on developmental phases and milestones. These categories include infants, toddlers, preschoolers, school age and adolescence. A preschool age child most frequently is defined as a child between 36 and 72 months of age and not in kindergarten. Children in kindergarten are frequently in a different type of a school setting. They are considered to be in the school age category even though they may be between 60 and 72 months of age. Therefore, a preschool age child will be contextually defined as 36 to 72 months of age who has not yet started kindergarten.

Autism Spectrum Disorder

An autism spectrum disorder is a medical diagnosis. ASD, in this study, will be considered as an autism spectrum disorder that was diagnosed by one of the child's physicians.

Mother

Lastly, there are many definitions as well as ways to be a mother. Traditional motherhood, however, is what is being considered in this study. Given the methodology of phenomenology, and the usual and customary use of small sample sizes in a study of this nature, limiting the definition of motherhood is necessary. A mother will therefore

be defined and considered as the natural birth mother or adoptive mother who lives with and has primary care giving responsibilities for the child.

Conclusion

In conclusion, the prevalence of ASD in the population has increased significantly since first described in the 1940s. The complex health care needs of children with ASD along with the unique developmental characteristics of these children may require an innovative approach to health care. The significance of studying and understanding more about the health care experiences of mothers of children with ASD can reveal concerns, feelings, resources, and barriers in the delivery of health care. Understanding these is an important step toward meeting this growing population's health care needs.

Chapter 2: Review of Literature

So many nights I have lain awake as tears-mixed-with-prayers dampened my pillow.

I've put in a lot of time in the dark, feeling heavy and helpless and terrified for a future I can't predict. But all of a sudden the future has revealed itself from the other side, and it's being held up before my eyes like an Olympic torch. Whatever has led us to this--years of speech therapy, hours upon hours of my own input based on instinct and a few educated guesses, his father's incredible talent for showing him a way to walk through this world--William can see his dream and it looks good. In fact, it looks perfect. And he is telling me all about it.
(Harland, 2002, p. 22)

Introduction

Autism presents a struggle for the child, the parents, and the health care provider.

The mystery of what causes it and what might help reduce or diminish its effects on development adds to this struggle. As Kim Harland (2002) describes above, the diagnosis and treatment of autism is full of unknowns and involves a multifaceted approach. It requires the commitment of many: the medical community, educators, parents, and family members, and each hold a piece of the puzzle. This chapter will summarize the current state of the literature of autism related to families, mothering, and health care for this population.

This review of literature was completed using both health-related and educational databases. Databases were searched for pertinent research studies as well as current health information. Key words used in these searches included *autism*, *mother*, *preschool*, *health*, and *health care*. The databases searched included PsychInfo, ERIC, CINAHL, Medline, and PubMed. All articles were limited to English. In order to identify appropriate articles, abstracts were read to determine the degree of relevance to the topic. Pertinent articles were then used to identify both seminal and additional works.

It is apparent through this comprehensive literature search that nursing research is lacking in the specific area of a mother's experiences during health care visits with her child with ASD. A review of the relevant literature follows.

Families with Children with Disabilities

Families are central to the care of a child. Evidence of this is clearly supported in health care by the use of frameworks such as family-centered care when providing care to all children (Hutchfield, 1999). Children require the nurturing, care, and support of a family in order to optimally grow and develop. Frameworks for nursing and care giving, such as family-centered care, recognize the importance of the partnership between parents and health care providers in meeting the growth and developmental needs of a child. Recognition of the family as a constant in the child's life, and the belief that parents have the child's best interests at stake, underpins the assumption that families are a child's greatest resource (Hutchfield).

Children with disabilities, and specifically those with ASD, require an even greater amount of family support in order to meet developmental milestones (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008). Disabilities create more complexity in care and increase the long-term commitment of families. This is because the typical developmental progression of families becomes altered when a child with a disability is born. These families often are unable to meet typical family developmental stages. For example, the stage of "launching children" into adulthood (Langford, 2004) may not be met when a child has a significant disability such as autism. Families of children with disabilities invest and sustain a considerable amount of psychological, financial, and

physical support to their children over time (Guralnick, 2004). Their focus is on complex issues such as assuring that the long-term health and well-being of their children's needs are met. This can create a great deal of stress in their lives (Cassidy et al.; Guralnick; Sivberg, 2002b).

Over time, the stress and exhaustion associated with having a child with a lifelong disability takes its toll on the family system. This stress has even led some parents to express a difficulty in finding the "meaning" in their lives. Sivberg (2002a) found this to be true when he looked at coping strategies and parental attitudes in parents of children with autism. He also noted that mothers are especially vulnerable to these stresses due to the frequent and increased day-to-day care giving responsibilities required by their young children.

Disabilities present ongoing and life-long challenges which begin with the medical diagnosis. However, this diagnosis only marks the start. The diagnosis does not offset the life-long challenges and stigmas that families have on a day-to-day basis in caring for their children (Gray, 2002). The stigmas associated with caring for a child with a disability can be exceptionally difficult. It is even more difficult when the child is diagnosed with ASD, as this greatly affects social interactions and behaviors. For these families, life is changed. It will not be what they anticipated nor what they had planned for their family's future (Briskin & Liptak, 1995). Support from professionals, the community, and other family members is essential for these families (Cassidy et al., 2008; Pinto-Martin, Souders, Giarelli, & Levy, 2005). This support may include psychosocial, financial, as well as service-based assistance.

Mothers of Children with ASD

Mothers, in the early years of a child's life, frequently take a larger role in many aspects of child rearing than fathers. Part of this mothering role includes aspects such as nurturing and caring for the child. Consistent with this role and concept, mothers of children with ASD have an even increased involvement in these aspects of their child's care (Duarte et al., 2005; Haussler & Kurtz-Costes, 1998). This includes not only a child's usual daily care activities, but also an expanded role in the areas of the child's educational programming as well as ensuring that the child's health needs are met. Historical descriptions of mothers who have children with autism describe them as being "cold" and non-nurturing (Kanner, 1949). In the past, this has stigmatized these mothers. Even though today it is clear that this is not a cause of autism, mothers may still feel some stigma and stress associated with this.

The increased amount of stress that mothers of children with ASD exhibit has been documented numerous times (Duarte et al., 2005; Fitzgerald, Birkbeck, & Matthews, 2002; Pelchat, Lefebvre, & Perreault, 2003; Pisula, 2007). It has also been noted that the more disabled or difficult the child's behavior is, the greater this increase in stress level becomes (Fitzgerald et al., 2002; Hastings et al., 2005). Additionally, mothers and fathers differ in their coping styles. It has been shown that mothers display an increased vulnerability to stress when compared with fathers (Gray, 2003). Coping strategies used by mothers often focus not only on participating and ensuring their child receives therapy, but also extending that therapy into their mothering role (Gray). This may present an internal struggle for mothers. Their role takes on a more therapeutic

focus rather than the usual nurturing and care-giving focus of mothers of typically developing children.

Self esteem and self worth are important aspects of one's ability to cope.

Johnston and Mash (1989) looked at overall parenting satisfaction in mothers and fathers of children with ASD ages four to nine years old. They found that mothers base the self evaluation of their ability to mother on the degree of the child's behavioral problems. The more difficult the child's behaviors are, the lower their level of self esteem related to their parenting abilities (Johnston & Mash). Additionally mothers, in general, tend to evaluate their competency as a parent on their own estimates of their ability to handle their own child's behaviors (Johnston & Mash). Because children with ASD have an increased number of behavioral deficits, it is likely that their mothers have an elevated level of stress that may lead to a decrease in self esteem related to their parenting role.

Lastly, mothers of children with disabilities often lack a social support network (Bromley, Hare, Davison, & Emerson, 2004). This can be especially true for mothers of children with ASD. Due to the increased intensity of the daily needs caused by their child's behaviors, these mothers are frequently unable to work outside of the home, leading to a decreased social network. Additionally, the young child with ASD's frequent behavioral difficulties minimizes the mother's ability to interact within the community, as well as with parents of typically developing children. Mothers of children with ASD become more socially isolated than other mothers.

Mothers of children with ASD do, however, have important strengths. Montes and Halterman (2007) documented the strong parent-child relationship they exhibit as

one of these strengths. These mothers are deeply bonded and invested in their child's therapies, treatments, and outcomes. This close tie has been shown to be fundamental in the success of their child's treatments and educational programming (Duarte et al., 2005). A study by Tunali and Power (2002) looked at how mothers of children with ASD coped and redefined the roles of motherhood in response to the stresses of raising a child with autism. They found that mothers created alternate ways of fulfilling their concept of motherhood in light of the special challenges that their child presented. These alternative ways included focusing and spending more time on their family, placing less emphasis on what others thought of their child's behavior, placing increased emphasis on spousal support, and increasing their tolerance to the ambiguities their child demonstrates (Tunali & Power).

Mothering any child has its difficulties. However, the complexity of mothering a child with autism is apparent. The diagnosis of an ASD increases overall stress, increases the everyday demands of child rearing, and takes an emotional toll on the self esteem and feelings of self worth of a mother. Mothers also develop a close and deep bond with their children. It is important for health care providers to understand more about the difficulties these mothers have.

Receiving the Diagnosis of Autism

The rise in autism and the chronic nature of the disorder makes this an important condition for health care providers to recognize and have knowledge about. Because of this, health care providers need to have the skill set to recognize the condition, refer the child appropriately for a diagnosis, and also provide other appropriate health care

services to a child with ASD. Pediatric health care providers play an integral role in the early identification and ongoing treatment of their patients with ASD (Barbaresi, Katusic, & Voigt, 2006). One study indicated that almost half of the physicians surveyed reported that they care for at least 10 children with ASD (Johnson et al., 2007). Caring for children with ASD is part of their everyday practice.

Appropriately, primary care providers are frequently the first health care provider to both suspect and screen for an ASD. This is the result of a successful drive to increase screening for autism at earlier ages and in all children undergoing routine health care visits (Rhoades, Scarpa, & Salley, 2007; Volkmar, Wiesner, & Westphal, 2006). Although it is clear that there are increasing numbers of children diagnosed with autism, it is not completely clear if this is due to an increase in the actual incidence of autism or if it is due to the broadened clinical definition of the disorder that has occurred over time (Fombonne, 2003a). An indication of this broadened clinical definition is indicated by the change in terminology from autism to autism spectrum disorders (Fombonne, 2003b; Johnson et al., 2007).

Diagnosing a child with an ASD also presents challenges to health care providers. Providers may be expected to act as a diagnostician, service provider, and counselor all in one visit (Shevell, 2006). This takes a considerable amount of skill, experience, time and patience. Therefore, health care providers may not be able to address all parent concerns at the time of a health care visit due to limitations in appointment times (Kerrell, 2001; Stein, 2002). This can lead to unhappiness and a poor relationship between provider and parent.

Health care providers are also answering increased numbers as well as more difficult questions from parents. Today, parents have access to increased amounts of health information than they had in the past (Stein, 2002). Technology, such as the internet, has lead to this broadened base of knowledge and medical information. Therefore, health care providers must be exceptionally current as well as knowledgeable about available treatments.

The current number of children with a diagnosis of ASD is challenging for HCPs. Even with the increased number of children diagnosed, and a greater number of health care providers screening for ASD, there continue to be many barriers in both the diagnosis and treatment of ASDs (Krauss et al., 2003; Ruble, Heflinger, Renfrew, & Saunders, 2005). There is no clear cause and no cure; therefore, diagnosing a child with ASD and subsequently delivering this diagnosis to the parents can be stressful for health care providers. Studies show that health care providers frequently are uncomfortable and even lack confidence in making such a diagnosis (Minnes & Steiner, 2009; Pelchat & Lefebvre, 2004). Therefore, giving this diagnosis to a parent without being able to provide clear information related to a cause can affect the relationship between the parent and health care provider.

The Complex Health Care Needs of a Child with Autism

Increased Frequency and Number of Health Care Visits

Typically developing children are frequent consumers of health care services especially in their early years. They visit the health provider regularly for routine health promotion, immunizations, monitoring of growth and development, and also for illness.

Evidence reveals that children with autism see their health care providers with even more frequency than typically developing children (Liptak, Stuart et al., 2006). Children with ASD present with ongoing needs and require chronic medical management (Myers, 2009).

Several studies document the health care expenditures of children with disabilities and specifically children with ASD. Estimates of health care expenditures for this population have been upwards of 10 times greater for children with autism than that of typically developing children (Mandell, Cao, Ittenbach, & Pinto-Martin, 2006). Several studies also support the claim that a diagnosis of autism places a significant financial health care burden on these families (Croen et al., 2006; Liptak, Stuart et al. 2006; Shimabukuro, Grosse, & Rice, 2008). These expenditures include the cost of frequent health care provider services and take into consideration the increased number of medications and costs associated with those medications.

Comorbidities Lead to Complexities in Health Care Needs

Children with ASD frequently suffer from comorbid health conditions (Gurney, McPheeters, & Davis, 2006; Liptak, Stuart et al., 2006; Luther, Canham, & Cureton, 2005). These conditions include seizures, increased environmental allergies, gastrointestinal complaints, psychiatric diagnoses, behavioral difficulties, and sometimes intellectual deficits. These health conditions lead to a greater number of health care provider office visits for children with ASD than their typically developing peers have (Liptak, Stuart et al., 2006; Niehus & Lord, 2006). In light of the multiple medical

diagnoses and chronic health concerns of children with ASD, this frequent use of health care services is necessary.

Several neurological and genetic diagnoses are prevalent in children with ASD. Among these neurogenetic diagnoses are Fragile X, tuberous sclerosis, and neurofibromatosis (Johnson et al., 2007). These coexisting neurological comorbidities can complicate the diagnosis, prognosis, and treatment of ASD. Epilepsy also occurs at an increased rate in children with ASD (Fombonne, 2003b). In addition, cognitive impairments affect more than 50% of children with autism (Fombonne, 2003a).

In addition to neurological and genetic comorbidities, children with ASD may have an increased rate of environmental sensitivities, allergies, and ear infections, as well as gastrointestinal complaints. Gastrointestinal disorders and symptoms have frequently been a concern and complaint of parents who have had a child with ASD. A study by Niehus and Lord (2006) did not find a significant amount of chronic gastrointestinal problems in children with ASD. However, gastrointestinal symptoms, such as food intolerances, diarrhea, and stomach aches, continue to be a frequent complaint for this population of children (Cole, 2008). Data continues to be insufficient in this area and parents may trial elimination diets or food supplements in order to alleviate these perceived or real symptoms (Hanson et al., 2007). Evidence does support that children with ASD have increased numbers of upper respiratory infections, ear infections, and use of antibiotics (Neihus & Lord).

Children with autism also present with coexisting psychiatric and behavioral problems. These include obsessive-compulsive disorder, anxiety, depression, inattention,

and hyperactivity (DHHS, 2008). The addition of these particular diagnoses with an ASD diagnosis further complicates the social and behavioral difficulties of these children.

One of the difficulties in treating comorbidities in children with autism is that the children's biological response to usual medical treatments and therapies for these conditions is frequently unpredictable (Volkmar et al., 2006). It is speculated that the primary reason for these atypical responses is due to the wide range of behaviors these children exhibit, further evidence that these children have increasingly complex medical needs (Volkmar et al., 2006). These atypical responses may also be due to the complicating factor of having multiple medical diagnoses and the treatments for these diagnoses. These children's reactions in the environment are not typical and neither are their reactions to medical treatments.

The Medical Home

One important recommendation for children with a developmental disability, such as ASD, is that they have what is considered a "medical home". A medical home is a primary care provider that serves as a central case coordinator for the child. Even though children with ASD see multiple specialists for comorbidities, there is evidence that children with autism spectrum disorders frequently lack a medical home (Krauss et al., 2003; Mandell et al., 2006). This lack of a medical home can adversely affect the child's delivery of health care leading to a less than holistic approach. Individual providers may repeat tests or prescribe medications without fully understanding other treatments that the child has undergone or has used. This is evidence of another gap in providing health care to this population. The complex needs of the child with ASD requires important

collaboration and case coordination between all of the child's providers (Kerrell, 2001).

Without a "medical home", coordination of care is compromised.

Accessing Health Care Services

Even though health care expenditures provide evidence of the increased use of health care services among the population of children with autism, parents continue to feel frustrated that they are not receiving appropriate and necessary health care services (Nesbitt, 2000). These unmet needs primarily consisted of specialty care for comorbidities, support services, and services for delayed or postponed care (Kogan et al., 2008). Parents of young children with autism may have the inability to address some health concerns in a timely manner because of the need to prioritize health concerns due to multiple symptoms and diagnoses.

Interestingly, children with autism have more difficulty accessing specialty care than children with intellectual disabilities or other special health care needs (Kohler, 1999; Kogan et al., 2008; Minnes & Steiner, 2009). A surprising one-third of parents of children with autism report an access to care problem (Krauss et al., 2003). This difficulty in accessing care was even more pronounced in children whose families had private health care insurance instead of those with public health care coverage such as Medicaid (Krauss et al.). So even though there is a significant increase in the health care expenditures and services provided to children with ASD, there is evidence that families continue to have difficulty accessing necessary treatment and care for their children. Clearly, more information is needed to understand the gaps that are occurring in providing care to this population of children. It is not that they are not visiting their

health care providers, but rather the care that is received is not addressing the problems or concerns that parents have regarding health care for their children with autism.

Treatments and Health Care

It is difficult to determine the prognosis of a child diagnosed with autism. The unknown nature of the cause of autism along with a lack of researched and documented medical treatments for the disorder is one reason (Volkmar et al., 2006). To date, early access to therapeutic interventions, that include intensive speech and language therapy and behavioral interventions, are one of the few treatments that have been shown to be helpful for children with autism. Various medical treatments, educational interventions, complementary and alternative medicine (CAM), and medications have been used by parents both with and without the advice of health care providers.

Educational Strategies

Research supports the usefulness of early behavioral and educational interventions as the primary treatment for autism (Myers, 2009; DHHS, 2008; Volkmar et al., 2006). These educational interventions include special teaching methods that use a behavioral basis as well as behavioral interventions. Additionally, intensive speech and language therapy is also an essential part of the child's educational plan because of the child's deficits in communication. This therapy may also utilize alternative methods of communication or augmentative communication devices. However, these therapeutic and educational interventions, as well as their intensity, can vary greatly between programs. Therefore, response to these interventions can be difficult to predict (Volkmar et al.).

These educational interventions are one of the few consistent methods of enhancing the social and language development of children with ASD (DHHS, 2008; Hume, Bellini, & Pratt, 2005). Privately accessing these services can be costly. They are usually provided through the local school district or state funding, however many families do not feel that they receive enough of these services. Due to the cost, few families find themselves financially able to provide the degree of educational and behavioral intervention they feel is necessary for these children. Additionally, these services are often excluded by private insurance or third party payers. Parents, and especially mothers, find themselves at odds with these providers because of limited services due to the excessive financial burden on local agencies (Gray, 2002).

This inability to access an increased number or higher level services is yet another burden and source of stress for mothers. However, this is starting to change. Just recently, the state of Missouri became the 21st state to pass legislation requiring private insurance companies to cover both diagnosis and treatment of autism for children who are under the age of 18 (HB 1311, 2010). This bill will take effect in January of 2011 and will specifically cover applied behavioral analysis therapy, an educational intervention.

Psychotherapeutic Medications

Children with autism can have considerable behavioral symptoms that need to be managed through the use of psychotropic drugs. Mandell et al. (2006) studied the use of psychotropic medications in a population of Medicaid-enrolled children with ASD and found that over 50% of these patients used at least one psychotropic medication.

Pharmacological treatment of behavioral symptoms for autism is both available and widely used. These medications include antipsychotics, such as Risperidone, and selective serotonin reuptake inhibitors (SSRIs) for the treatment of depression, anxiety and obsessive-compulsive behaviors (Myers, 2009; Volkmar et al., 2006). Stimulant medications, such as Methylphenidate, may be used to address inattention and hyperactivity (Myers). Additionally, other medications that may be used to treat psychiatric and behavioral symptoms include benzodiazepines, anticonvulsants, and mood stabilizers (Myers).

Psychotherapeutic medications are primarily used for the treatment of associated behavioral symptoms; however, they are not helpful as a core treatment of the autism spectrum disorder itself. Given the range of maladaptive behaviors, both psychological and psychiatric, treatment with these medications have varied results (Gurney et al., 2006; Volkmar et al., 2006). Many of these pharmacological agents can also have disturbing side effects such as tardive dyskinesias and tics. Also, the safety and efficacy of these medications has not been well researched or has had limited testing in children with autism (DHHS, 2008).

Complementary and Alternative Medicine

Given the mysterious nature of autism and its severity in some children, it is not surprising that families look to unconventional treatments for this unconventional disorder. However, many of the complementary and alternative treatments and medications lack a substantive scientific basis and some are not even safe (DHHS, 2008;

Volkmar et al., 2006). Therefore, many health care providers do not recommend the use of CAM therapies for their patients.

In the study by Hanson et al. (2007), evidence has shown that families are not only increasingly turning toward the use of CAM therapies, but also to the alternative providers that recommend them. In particular, the use of a physician who specializes in biomedical therapies called a “defeat autism now” (DAN) doctor. This is primarily due to a view that CAM providers, including DAN doctors, offer a more supportive approach to treatment than traditional providers (Hanson et al.). It may also be due to the lack of scientifically supported treatments available for autism.

Parents are frequently dissatisfied with the traditional pharmacological treatments offered by their health care providers. The reason for this may be because psychotherapeutic medications only treat the behavioral symptoms of autism and do not offer an answer or a cure for the basis of the behaviors. Additionally, these psychotherapeutic medications require frequent adjustments in dosage to achieve results, which can be frustrating to parents. The partnership between traditional health care providers and the parents who choose CAM treatments for their children can, therefore, become strained. Because of this, many parents use CAM in their child’s treatment regime but are hesitant to report its use to their health care providers (Hanson et al., 2007).

Treating autism is a challenge for health care providers and frustrating for parents. Outcomes are often unpredictable. Parents feel helpless with their inability to meet the complex needs of their child and often look outside of the realm of conventional

medicine for treatment. Some of this is due to dissatisfaction with traditional medicine and with the inability of their health care providers to treat their child's disorder.

Providing Health Care to Children with Autism

Health care providers caring for children with ASD and their families admit that they have concerns when caring for this population. These concerns include feelings of inadequacy as well as a lack of confidence in treating and caring for the child with an ASD (Minnes & Steiner, 2009; Pelchat & Lefebvre, 2004; Rhoades et al., 2007).

Certainly the increasing prevalence of ASDs has lead to increased awareness of the need to screen for the disorder; however, health care providers continue to have difficulty providing the holistic care that is required of a diagnosis of autism due to the high number of comorbidities associated with ASD and time constraints. Some of this care is centered around understanding how to manage the care and comorbidities as well as knowing the resources necessary for families with a child with autism (Johnson et al., 2007). Clearly, gaps exist in the provision of care for this population.

The family of a child who has a disability has significant needs. Those needs includes increased amounts of health information, increased amounts of health education related to their child's specific disabilities, and increased time from the HCP to provide this information (Guralnick, 2004). It has been shown that when mothers of children with autism have increased amounts of information and resources available, stress and anxiety are both decreased for the mother (Pelchat et al., 2003; Tsai et al., 2008). The complexity of ASD also necessitates a multifaceted, but individualized, approach to the child's medical needs. This approach must take into account the child's individuality,

strengths, and limitations along with the family's unique characteristics (Johnson, Kastner, & The Committee/Section on Children With Disabilities, 2005).

What then are the concerns of the mothers? What might be areas of health care that providers are missing when they provide care to children with ASD? Several studies have demonstrated that families consider their health providers to be aware and "up to date" on the new aspects of care related to autism. However, families feel that providers lack an understanding of the impact that the disorder has on the family (Brachlow, Ness, McPheeters, & Gurney, 2007; Briskin & Liptak, 1995; Liptak, Orlando et al., 2006). Families also desire more information that is specific and individual to their child's condition, which can be difficult given the wide range of associated behaviors and the range of disability inherent in a diagnosis of autism.

Another area of concern mothers have with their health care providers is the perception that providers are not always listening or taking their concerns seriously. A traditional approach in providing pediatric care is the use of techniques such as reassurance or even allowing more time for a child to achieve a developmental milestone (Caronna et al., 2007). Professional experience often demonstrates to providers that simple reassurance to parents is often all that is necessary. However, parents frequently have important concerns and even a "sixth sense" that something may not be quite right. Parents who are simply reassured and sent on their way may not feel respected or may not feel that their concerns are important. Certainly, health care providers will not always agree with parents' concerns, or even a parent's report of child achievement, but in the case of a parent with a child with ASD, nothing is ever quite usual or occurs as expected.

Nurses have a unique opportunity in the provision of health care for a child with autism. They bring skills, such as case coordination, collaboration, anticipatory guidance and problem solving, to the care they provide (Davis & Steele, 1991). The importance of these skills is that they can increase a provider's understanding of the unique needs of both the family and the child with special needs. Nurses also serve as an important support for parents. One of the ways this support can be provided is through helping parents sort out the advice they receive, as well as the volumes of health information now available (Cade & Tidwell, 2001). The patient-centered focus of nursing provides an important and tailored approach to caring for the child with autism.

There is evidence that health care providers are not fully meeting the needs of their patients with ASD. Providers need to be aware that stress is high in mothers of children with autism (Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001). The evidence exists that families desire not only more health information about autism from their providers, but they also desire their providers to have more autism specific training (Rhoades et al., 2007). However, what is not fully understood are the important aspects of the health care visits themselves that are deficient in meeting the needs of the mothers.

Collaboration and Partnerships

Collaboration between mother and provider is an important part of any health care visit, but it becomes even more essential when the patient is a child with ASD. With parents' increased access to health information, there is a need to ask more questions and develop a deeper partnership with health care providers. Additionally, providers are seeing more patients with not only a diagnosis of autism, but also with multiple

associated comorbidities. A typical visit to the health care provider is anything but typical when it is for a child who has a diagnosis of autism. The visit requires an enhanced relationship between mother and provider with an increased level of collaboration.

There is evidence of the importance of planning and collaborating with parents when a child with autism has the need for health care. Parents are frequently good predictors of their child's unique reactions to new or unusual surroundings. There have been only a few studies that have looked at interventions focused on this type of planning and parent involvement for the child with ASD. Two of the studies looked at surgical outcomes for children with autism whose parents were contacted prior to the surgical date (Van Der Walt & Moran, 2001; Seid, Sherman, & Seid, 1997). This prior contact with the parent allowed health care providers an opportunity to gather important information in order to plan for the child's anticipated surgery. Van Der Walt and Moran found that early communication with parents of children with autism, in order to individualize the anesthetic plan for the child's surgery, led to a decrease in patient stress and a smoother post operative phase for the child as well as parent stress. Similarly, Seid et al. also found that early involvement and communication with parents of children with autism undergoing ENT surgery led to quicker discharges and less complicated postoperative courses. Both of these studies can serve as evidence of the importance of listening, communicating, and collaborating with a parent of a child with ASD and how this understanding can lead to a more positive outcome for the health care experience for the child with ASD.

What are the Mother's Needs?

There is little nursing literature that identifies specifics regarding the needs of mothers during health care visits for their child with ASD. Certainly the literature indicates that mothers are dissatisfied with the lack of information received and the difficulty they have in accessing health care for their child (Minnes & Steiner, 2009; Ruble et al., 2005). However, there is a lack of information regarding these mothers' specific needs and concerns related to their children's health care experiences.

What does exist in the literature is evidence that mothers of children with autism, have a keen sense and understanding of their child (Caronna et al., 2007; Inglese, 2009; Nadel & Poss, 2007; Souders, Freeman, DePaul, & Levy, 2002). Researchers also know that empowering the mother of a child with ASD leads to an overall better outcome for the child (Kuhn & Carter, 2006). Mothers are most frequently the caregiver that interacts with the health care providers. This is especially true in the early ages of a child's life. Therefore, mothers are uniquely situated to provide important information regarding their child with ASD's health care experiences.

It is known that children with ASD react better to routines or familiar situations and are easily distracted and overwhelmed by events and stimuli. Positive interactions are also important and can pave the way for future successes for these children. The health related literature identifies all of these techniques as possible ways to improve the outcome of health care visits for children with ASD. However, there are very few studies that have investigated these techniques or proven them effective in increasing the quality

and outcome of the health care visit for children with autism. Health care visits require a more thoughtful approach when providing care to a child with an ASD.

Conclusion

Should health care providers assume that mothers want more technical information? Do the mothers need more social support? Are mothers in need of more time with the health care provider, or do they need the exam room to be less distracting so that their child has less opportunity to exhibit negative behaviors? Many quantitative studies have looked at either survey responses or questionnaire comments of parents of children with autism. But few studies have asked and listened to the real concerns of mothers related to their child's health care experiences. In order to increase the understanding of these mothers' needs, and in order to improve the relationship between the mothers and health care providers, someone needs to ask and then listen to their concerns. Listening to the mother's voice, the person who knows the child best, is a necessary step toward a deeper understanding of the unique needs of both the child with ASD and their mother.

Chapter 3: Methodology

“For phenomenology does not argue for the abolition of traditional science, but rather for its appropriate use: that is, for its use in levels of study in which participants’ meanings and interpretations do not figure.”
(Leonard, 1994, p. 45)

The Interpretive Phenomenological Approach

Heidegger developed his phenomenological viewpoint around the concept of “being” and the meaning of “being” a person rather than in terms of “a being” (Leonard, 1994). These concepts form the basis of phenomenology. Phenomenology can offer important insights into a person’s experiences as the researcher looks at those experiences within the context of that person’s life. Heidegger says that a person and their “world” cannot be separated from each other, as each shapes the other (Leonard, 1994). Therefore, in studying people and experiences, they must be studied in context in order to gain understanding. This is because experiences only make sense against the background from which they were developed and cultivated.

Interpretive phenomenology was chosen as the methodology for this study. Several goals of interpretive phenomenology made it an appropriate method. These goals include hearing and understanding the voice of the participant, accurately presenting this voice, seeking a greater understanding of the phenomena, and uncovering differences and commonalities of events (Benner, 1994). The purpose and specific aims of this study, to gain an understanding of the health care experiences of preschool children with ASD through the mother’s perspective, fit well with the overall goals of interpretive phenomenology.

Understanding the experiences of caring for and living with a child with ASD requires an approach that allows for situated understanding. There is a uniqueness with which autism affects a child and a mother. Everyday life for the parent and a child with autism is not ordinary when compared to other families. Even usual events, such as meeting health care needs, can become extraordinary. Therefore, studying and understanding the meaning of events of this nature should be done in context. A phenomenological approach would argue that meanings are only significant if they are considered within the context and surroundings of the environment. Likewise, Heidegger disagrees with traditional science in saying that it can limit one's ability to understand the human experience and further restrict the ability to generate answers to important questions (Leonard, 1994). The benefits of using a phenomenological approach is that it can help uncover and discover experiences as they are and in the context of the person's world. More specifically, Heideggerian phenomenology focuses on a viewpoint that the experiences center on the relationship of the person within their world (Leonard).

A person is always situated in their world (Pohlman, 2003). This world is comprised of relationships, practices, environment, language, and a sum total of everything that is related to the person (Leonard, 1994). This "world" becomes central to understanding the person, and the person cannot be removed from this context. Language is a tool that can be used to describe, narrate, and articulate meanings of the world in which one is situated (Leonard). It is a way for a person to share both their world as well as their self. Describing experiences, as they are, is the goal of interpretive phenomenology (Broeder, 2003).

Phenomenology is concerned with the correct interpretation and understanding of the experience. It is not focused only on amassing knowledge or facts (Gadamer, 1975). To understand experiences in a true sense is not to simply gather large volumes of words and texts, but rather it is to analyze and understand them through the eyes of the participant. Gaining a deeper understanding of what the experience means to the participant and how it affects the way the person views and conducts their life is how text is used. This leads to greater understanding. The power of understanding can then lead to a more engaged and humane practice of science (Benner, 1994).

An interpretive phenomenological approach is an appropriate method for studying the meanings and experiences that were the focus of this study. It both required and allowed the researcher to actively engage in a reflective process with the stories and narratives from the participants (Conroy, 2003). Phenomenology is also a process in which the researcher recognizes the importance of the participant's "world" through the interpretation of the text. The use of this methodology magnified the voice of this population, mothers of preschool children with ASD. Additionally, the interpretive texts developed from this research served to articulate the concerns and feelings of these mothers in the context of their children's health care visits and needs. These texts provided information that could lead to improved partnerships between mothers, children, and healthcare providers.

Forestructure of the Researcher

Forestructure is the background, experiences, and prior knowledge that one brings to the situation at hand. This forestructure cannot be avoided nor can it be unprejudiced.

It becomes important for the researcher to identify and explicitly describe this forestructure and how it has shaped the focus of the study. The process of interpretive phenomenology requires the researcher to be reflective and engage in reasoning about specific situations as well as the texts and transcripts of the participants (Benner, 1994). This engagement is part of the interpretive process.

My background in pediatrics and working with children and families of children with ASD provided me with some pre-understandings for this study. This background supports this phenomenological methodology in two ways. First, the world in which the participants live is not totally foreign to me; however, because I do not live in it, I do not fully understand it. I have experienced the world from the viewpoint of a provider of health care services to the preschool child with ASD. Working as a pediatric nurse in a school setting in which I cared for preschool children with ASD, I have interacted frequently and in many situations with both the child with ASD and the parent. Given my strong pediatric background, the care that I provide as a nurse is heavily based in family-centered care. Family-centered care focuses not only on the child as the patient, but on the child as part of a family. Realizing that each child is part of a larger unit, the care that the child needs and receives, impacts the whole family system. I am very conscious of the importance of the mother and family members in the care of all children and especially a child with special needs.

Second, I am a mother of three daughters. The personal experiences of caring for my own children have shaped my understanding of both motherhood and what it means

to be a mother. Although my children do not have developmental disabilities, my position as a mother helped me connect with the mothers who participated in this study.

Interpretive phenomenology's foundation comes from understanding that interpretation is grounded in the forestructure (Plager, 1994). These forestructures consist of one's background and one's point of view, which both affect the interpretation process. Rather than detracting from the interpretations the investigator makes, in interpretive phenomenology, this forestructure can add to the credibility of the discoveries once they are laid out and described (Plager, 1994). Therefore, these pre-understandings are important. They supported my ability to be an active listener in the stories and narratives of the participants. They also provided additional insights into the voices of the mothers and helped in my understanding and identification of important themes in the text. However, because I do not have a child with a disability, there is some naivety with which I approached this study. Understanding my personal stance and position, as the researcher, is important as these presuppositions did form a background for this study (Benner, 1994).

Sample

Sample Size

Sample size is small in a phenomenological study. Size should be large enough to provide saturated and rich data, but manageable for the researcher to analyze the text (Benner, 1994). The quality and depth of the text is more important than the number of participants in interpretative studies. Sample sizes vary, however, and it is recommended that the participant number range from 5 to 25 (Collingridge & Gantt, 2008; Creswell,

2007; Polkinghorne, 1989). Therefore, the anticipated number of participants for this study ranged from 8 to 14, or until data saturation. The final sample size was 11 participants.

Selection Criteria

The focus of this study was to understand the mother's perspective of the health care experiences of her child with ASD. Therefore, participants for this study consisted of mothers of preschool children with a diagnosis of ASD. These mothers all had primary care giving responsibilities for their children.

Inclusion criteria. Inclusion criteria for this study included only mothers of preschool age children diagnosed with ASD. This was used to minimize confounding and complicated themes related to gender differences in child rearing. All mothers that participated in the study were biological mothers that lived in the home of the child who had primary responsibilities in caring for the child. Additionally, all mothers enrolled in this study spoke English. This was due to the nature of the methodology and the need for multiple face-to-face interviews and need to reduce confounding issues related to translation. Lastly, all mothers enrolled in this study were at least 18 years of age.

The preschool age child was defined as a child between 36 to 72 months of age and was not attending kindergarten at the time of initial enrollment. Typically, the preschool age has some overlap in the fifth year of life, with some children starting kindergarten during that fifth year. Several of the participants had children who were five, but all were enrolled in a preschool program and had not yet started kindergarten.

ASD is a medical diagnosis, but children may also meet educational criteria for special education services. For this reason, the criteria of “diagnosed” with ASD was considered as a medical diagnosis of ASD, given by one of the child’s physicians. The mother’s report of the medical diagnosis of ASD was sufficient for the researcher to qualify them for participation. Additionally, all participants completed a behavior rating scale for their child. Scoring from these scales demonstrated that all participants’ children fell into the borderline or clinical range of autistic behaviors.

Exclusion criteria. Several exclusion criteria existed for this study. First, fathers and male primary caregivers were not included since the focus of the study was from the perspective of the mother. In addition, mothers and fathers differ in their child rearing practices. The second exclusion criterion pertains to mothers. Female caregivers who were not primary caregivers, or not considered the mother of the child, were excluded. Additionally, mothers that did not live in the home or did not have primary care responsibilities for the child were also excluded. The aims of this study focused on discovering the meanings of mothering a child with ASD as well as understanding how this disability affected the motherhood role for these women. This is better accomplished if the mother has primary care giving responsibilities for the child. Also, mothers of preschool age children between 36 and 72 months old that had started a kindergarten program prior to the first interview were not included in this study. This was due to the focus on preschool age children. Once children start kindergarten, they are considered school age and no longer preschoolers. Lastly, given the pilot nature of this study,

participants who did not speak English were not included. This was to increase the strength of the data as translation can compromise the quality of the narratives.

Source

Participants for this study were recruited through a parent support group. This support group was a list-serve set up through Missouri Families for Effective Autism Treatment (MO-FEAT). MO-FEAT is an advocacy organization that provides information and resources for parents of children with autism. The executive director of this organization posted a recruitment flyer for this study on their list-serve that was also emailed to parents that subscribe to their communication alerts.

Additionally, it was planned to also recruit participants through the TouchPoint Autism Services office. TouchPoint Autism Services provides a range of services and support for not only the child with autism but also their family. Support for this study was obtained through the TouchPoint Autism Services Institutional Review Board. However recruitment from the MO-FEAT list-serve was so successful that no participants were recruited through the TouchPoint office.

Procedures for Data Collection

Recruitment

Recruitment occurred in two ways. First, recruitment flyers were widely distributed through the MO-FEAT list-serve. Interest in participating in this study was so overwhelming that the projected sample size was obtained within a week of the posting. The second recruitment technique was to use “word of mouth,” or passive snowball recruiting. My past experience with families of children with ASD had enlightened me to

the network of support these families have from each other. Therefore, additional flyers were provided to the first few participants that were enrolled in the study to pass along to friends who might also qualify to participate. However, no additional participants were recruited through this method. No active recruiting was done by the researcher for this study.

Method of Data Collection

The use of interpretive phenomenology, as a research method, required that the researcher gather information in order to increase understanding of the meaning of the life experiences in the context of that person's world. Consequently, language is how this was achieved for this study. Language involves descriptions, stories, and life experiences that help identify the person's perspective of the phenomena under study. In this study, the primary method of data collection was through interviews. The interviews used two interview guides that were adapted from other researchers and two guides that were developed by this researcher. Additionally, demographic data and a published behavioral assessment tool were also used. The use of demographics and the validated behavioral assessment tool were helpful in obtaining initial descriptions of the participants and their children as well as providing a baseline behavior rating for the children. Participants were all interviewed three times each over the course of four to six weeks.

Procedure

Institutional Review Board (IRB) approval for this study was obtained through the University of Missouri-St. Louis IRB. Interested participants contacted the researcher either through email or a phone call. The researcher then return contacted the

participants through a phone call and discussed the study with them, determining if they qualified to participate and were still interested in participating. Then an initial interview date and time was established.

Written and informed consent was obtained from the mother participant at the initial interview. The consent form was reviewed, in person, with each participant prior to the start of the first interview. All participants were also given a copy of the consent form to keep. Additionally, participants were briefed, regarding the consent form and information, at the start of each subsequent interview. Mothers were reminded that they could choose to withdraw from the study at any time during each of the interview sessions.

Interviews were conducted in a comfortable place of the participant's choosing. These settings primarily consisted of the participant's home. However, two participants were insistent in meeting and having interviews conducted at a local coffee house. These participants wanted to maintain the privacy of their homes and frequently met people for meetings at restaurants instead of their homes. These two participants both felt that these places provided them with confidentiality and were adamant that interviews take place in these locations; therefore, booths in the back of the restaurant were utilized for these two participants. For the most part, children were not present during the interviews, except in a couple of instances when children were home sick from school.

Permission to digitally record all interviews was obtained at the start of each interview. In addition to recording the interviews, field notes were also taken by the researcher immediately after interviews. These field notes were written. The

importance of the field notes was to document important thoughts with regard to the interview while the memory of the interview was still fresh. They were also taken in case technological issues arose with the recordings (Creswell, 2007). The use of both methods of data collection enhanced the quality of the data. Notes, however, were not taken during the interview so that the researcher could focus and participate in active listening.

Each participant was interviewed three times and each interview lasted between one and two hours. Interviews were semi-structured and used interview guides to organize the interviews (see Appendixes A-F). The first interview included the collection of demographic information and the last interview the administration of a behavior rating tool, the *Achenbach Child Behavior Checklist* (Achenbach & Rescorla, 2000). In addition, all three interviews included open-ended questions that allowed the participant to describe information. All interviews were then transcribed into text by a transcriptionist. Interview tapes, notes, and transcripts were then reviewed prior to the next scheduled meeting with the participants. Therefore, the second and third interviews started with clarification of any topics, thoughts, or questions from the prior interview.

Participant interviews were scheduled two to four weeks apart over a one to two month period. The purpose of this timeline was to allow for the capture of a recent health care visit. Despite this scheduling, only five of the participants had a health care encounter during the time they were enrolled in the study. Interviews gathered information focused on general and specific health care visits, information about the child, and information related to mothering.

Interview Guides

Each of the three interviews had a different composition, focus, and used a different interview guide. The use of interview guides was designed to initiate conversation and encourage dialogue (Pohlman, 2003). The table below clarifies when each of the interview guides and questionnaires were administered during the interviews. All guides were reviewed by an experienced qualitative researcher. They appear in Appendices A-F.

Interview Guide	Interview #1	Interview #2	Interview #3
Demographic Information	X		
<i>Health Care Visit Coping Interview Guide</i>	X		
<i>Understanding Mothering a Child with Autism Interview Guide</i>		X	
<i>Understanding Your Child with Autism Interview Guide</i>		X	
<i>Meanings of Motherhood Interview Guide</i>			X
<i>Achenbach Child Behavior Checklist</i>			X

Instruments and interview guides. There are two questionnaires that were used in this study. The first questionnaire was an investigator-developed demographic survey with selected demographic variables (see Appendix A). The use of the demographic survey provided a baseline of the study sample, participants, and their characteristics. It was also used to gain an initial understanding of each participant.

The second questionnaire administered was the *Achenbach Child Behavior Checklist (CBC)* (See Appendix B). It was completed during the third interview. The

Achenbach CBC is a general behavior rating scale consisting of 100 questions that utilize a 3-point Likert scale to rate behavior (Achenbach & Rescorla, 2000). The purpose of using the *Achenbach CBC* was to assess and describe general behavior patterns in the children. It provided a baseline of each child's general behavior so that comparisons could be made with regard to the degree of behaviors the children exhibit. Additionally, this tool would provide verification that the child's behaviors fell into the clinical range for autistic characteristics.

The *Achenbach CBC* was chosen because it specifically addresses behaviors for children ages 18 months to 5 years. Additionally, this checklist has been tested and shown to be a reliable tool for the assessment of child behaviors through parent report (Achenbach & Rescorla, 2000). However, the *Achenbach CBC* was not designed specifically for children with ASD, so it was necessary to use other descriptive interview data to capture important elements unique to the participant's child with ASD.

Four interview guides were developed and adapted for use in this study. The first guide was the *Health Care Visit Coping Interview Guide* (see Appendix C). This guide was used primarily to obtain general information about interactions and events that occurred during the child's health care visits. This particular guide was adapted from Lazarus and Folkman's *Stress and Coping Theory* (1984) and from Pohlman's *Coping Interview Guide* (Pohlman, 2003). The *Health Care Visit Coping Interview Guide* assisted in gathering descriptions of health care visits. It also elicited important feelings and concerns that mothers had during their child's health care visit. It was used at the initial interview to gather a retrospective description of the most recent health care visit.

It was also used again during the second or third interview if there was a recent health care visit that the child had while the mother was enrolled in the study.

The second guide developed was the *Understanding Mothering the Child with Autism Interview Guide* (Appendix D). This guide was developed by the investigator for this study. It was created to bring forth a better understanding of mothering a child with the unique characteristics of ASD. This range of characteristics, that children with ASD have, can present many challenges in mothering and caring for them. This interview guide helped capture those. It was used during the second interview.

The third interview guide that was developed and used was the *Understanding Your Child with Autism Interview Guide* (Appendix E). It was created to bring forth a better understanding of the participant's child with ASD. All children with autism have individual characteristics that can be very different from even other children with autism. These individual characteristics were captured through the mother's narratives and stories that this guide elicited. It was used during the second interview.

The *Meanings of Motherhood Interview Guide* (see Appendix F) was the last guide developed by the investigator for this study and it was used during the third interview. It was adapted from the work of Pohlman (2003) and SmithBattle (1992). It focused on obtaining descriptions and narratives of the participant's personal meanings of motherhood. It provided important information on how the participant's mother in relation to how they were mothered.

Data Management

The modes of data collection included digital recording of interviews, field notes, collection of demographic information, the use of a standardized questionnaire, and the use of interview guides. The data was maintained in a locked cabinet during the study. A transcriptionist was used to transcribe all interviews into text and all participants' information was de-identified. Participants' names and children's names were then changed to fictitious names to maintain confidentiality in the writing of the results of the study. At the completion of the study, all recordings, field notes and questionnaires were destroyed.

Protection of Human Subjects and the Institutional Review Board

Ethical Considerations

Prior to the start of the study, approval was sought and obtained through the University of Missouri-St. Louis IRB. All participants were over the age of 18 and English speaking. There were no exclusions based upon religion or ethnicity. The focus of this study was to gain an understanding of the health care experiences of children with ASD from the mother's perspective; therefore, no children were interviewed or directly involved in this study.

Confidentiality

Confidentiality was maintained for all participants in the study. Utmost care was taken to ensure that the surveys and interviews had all identifying information removed. All interview tapes, transcripts and notes were maintained in a locked cabinet. Permission to use de-identified transcripts and interviews for future studies or scholarly

endeavors was obtained from the participants through the use of the written informed consent.

Risks

No major risks were anticipated or encountered by the participants during the study. There was the potential of psychological distress and inconvenience in completing the interviews and questionnaires. Inconvenience was minimized by allowing the participant to choose the location and times of the interviews. Psychological distress was minimized by reminding all participants that they had the option to leave the study, as well as the right to refuse to answer questions or discuss topics, at any time. Several participants did become tearful during some of the interviews, but all wanted to proceed and complete the interview. Participants also received written and informed consent of the benefits and risks of participating in the study prior to the start of the study. A list of resources was available from the researcher in case of emotional distress, but not used.

Benefits

Potential benefits from the participation in this study included the prospect of contributing to the knowledge base of the health care experiences of a child diagnosed with autism. It is clear that there are increasing numbers of families receiving a diagnosis of ASD for their children. Understanding more about healthcare visits for a child with ASD along with learning more about what it means to mother a child with ASD are important aspects for healthcare providers. Another benefit to the participants was having an opportunity to have their voices heard regarding their experiences with their child with autism. Mothers of children with autism have many experiences that are

important for healthcare providers to hear and understand. This study provided them with a voice and a mechanism to teach healthcare providers how to better meet the needs of their children and themselves. Due to the growing number of children being diagnosed with ASD, the importance of this research in understanding the implications of health care experiences and behaviors in this growing population is notable.

Compensation

Participants did receive a nominal gift card in the amount of \$25.00 for each interview. This was provided in appreciation of their time and inconvenience. Financial support for this honorarium was provided by a scholarship received by the researcher from the Tau Iota Chapter of Sigma Theta Tau International Honor Society of Nursing.

Data Analysis and Interpretation

The questionnaires and interviews provided the data for this study. Transcribed interviews were analyzed by the researcher in three ways. These included the use of paradigm cases, thematic analysis, and exemplars. The use of these strategies were helpful in understanding the embedded knowledge and information that occurred within the text (Benner, 1994). Data analysis included a member check conducted through interpretive sessions held after all interviews had been transcribed. A summary of the participants and important demographic information is included in Appendix G.

A paradigm case is a specific case that enhances the understanding of a way of being in the world or doing a practice (Benner, 1994). A paradigm case is important because it provides a comparison for other cases. Paradigm cases are identified as being rich in content and meaningful and can be used to lead to a greater understanding of other

cases in the study (Pohlman, 2003). Interviews were reviewed for paradigm cases, and interpretive summaries were constructed for all participants. Through the creation and writing of the interpretive summaries, one particular mother's story stood out and was chosen as the paradigm case. This particular story provided a rich and deep understanding of mothering and the health care experience of a young child with ASD. It was used to shed light and illuminate parts of the other participants' interviews (Pohlman, 2003). This paradigm case was also helpful in identifying major themes in the study.

Thematic analysis was the second strategy used in the review of the interviews and text. Thematic analysis highlights meaningful patterns and concerns from the participant's interviews (Benner, 1994). It identifies the major themes of importance and increases the understanding of the experiences of the participants.

Participants' interviews were separated into individual files. The process of identifying themes started with the development of a blank table that was constructed by analyzing and reading each individual interview and comparing it to the specific aims of the study. Interviews were reviewed and highlighted for significant information and data. Then, like interviews were reviewed several times each and compared between participants; for example, all first interviews, then all second interviews, and then all third interviews. During the process of reviewing like interviews, key information was transferred to the large table under the appropriate specific aim and heading. After the table was completed and all interviews analyzed, the table was reviewed for recurring themes across participant interviews. This process of thematic analysis highlighted and made apparent recurring themes within the constructed table. Although the researcher's

forestructure is part of the interpretive process, there were no predetermined or defined themes that the researcher began with.

The last strategy used in data analysis was the identification of exemplars. Exemplars are used as stories or vignettes that help capture or illustrate the meaning of a situation or experience (Pohlman, 2003). They are important as they identify similarities and contrasts in the data. Additionally, exemplars can be useful in identifying attributes or operational definitions occurring in the text (Benner, 1994). They are another way for the reader to gain an understanding of the participant's experiences. Exemplars were used to support the significant themes that were identified.

Interpretive sessions were held to review the paradigm case and themes. These sessions included doctoral students who were also using interpretive and qualitative methodologies for their studies as well as an experienced qualitative researcher whose background is in interpretive phenomenology. Large portions of raw transcript were provided ahead of time to the other researchers that were participating in the session so that they could review them. During the interpretive session, discussion took place regarding the themes and meanings of the data. The use of these sessions strengthened the design of the study and verified the results of the analysis.

Demographic questionnaires and the *Achenbach CBC* were also used as part of the data in this study. Demographic questionnaires were used in the construction of the interpretive summaries as background information on the participants. The *Achenbach CBC* was scored as well. Information from this tool was used to identify and verify the presence of behavioral concerns in the participants' children since medical confirmation

of ASD was not required to participate in this study. All participants' children's behaviors were rated in the borderline or clinical range for pervasive developmental problems; this means that their parents' ratings of their behaviors were consistent with behaviors that could be considered a pervasive developmental delay, such as autism (Achenbach & Rescorla, 2000). It was anticipated that the Achenbach CBC would also help delineate the degree and type of other behavioral concerns among the children and therefore identify those children with greater difficulties during health care encounters. However, it was not as effective in revealing the degree of behavioral concerns as the interviews and therefore was not overly helpful during data analysis. Scores from the Achenbach CBC, for each child, can be found in Appendix H and I.

Validity and Trustworthiness of the Data

Evaluating the trustworthiness of a study is crucial to evaluating its merit and value (Lincoln & Guba, 1985). Lincoln and Guba focus on four criteria to establish the reliability of a study: credibility, confirmability, transferability, and dependability (1985). These four criteria were met in the analysis of the data in this study.

Credibility refers to the truthfulness of the findings while confirmability refers to the degree of bias in the results (Lincoln & Guba, 1985). Data analysis in this study was verified through a member check during the interpretive sessions. These sessions included outside researchers as well as a review of the themes with a doctoral committee member experienced in the interpretive phenomenological methodology. Large amounts of raw transcript were presented during the interpretive sessions which support the use of an audit trail. Credibility and confirmability was also evidenced by the prolonged

engagement of the researcher through the number and length of the interviews conducted. In order to reduce bias, the forestructure of the researcher was clearly stated up front. It should also be noted, however, that forestructure is considered an important aspect and strength of interpretive phenomenological work as it enhances the richness and deepness of the analysis (Benner, 1994). Lastly, there is evidence of triangulation as the data was analyzed through the use of a paradigm case, thematic analysis, and exemplars.

Transferability and dependability were also met. Transferability refers to the degree that those findings can be applicable in other contexts while dependability refers to the consistency of the findings (Lincoln & Guba, 1985). The use of three separate interviews that probed for rich descriptions supports the transferability of the findings. Dependability and the accuracy of the findings were verified through the interpretive sessions. Additionally, interpretive methodology relies on the adequacy, length, and depths of the interviews in order achieve those consistent findings (Angen, 2000). Interviews in this study averaged 1-2 hours in length and all participants were interviewed three separate times.

Chapter 4: Mary and John....Then Came David

We went to the park last Friday and [David] saw a girl from his class, they were on spring break. He goes, 'there's Sarah, I'm gonna go chase her' and they chased each other for 20 minutes and I could've died right then and there because all the social things we've been working on he did. He stayed with her, he played with her, he conversed, and I came home and I said it's working. The things that I never thought would happen are happening and I can't put into words the relief and the joy when I see him do it, and see the joy in him when he's like 'I just brushed my own teeth'. I'm like yeah, you did.

These are Mary's words about her son David who has autism. She describes the joy that she felt when David went to the park one day and simply played. He played just like all the other children did. This was something that did not come easy for David and took months of work to achieve. The following is a paradigm case. It is the story of Mary's journey through motherhood with a child who has been diagnosed with autism. It is a story of transformation that is filled with a spectrum of emotions; it is filled with frustration, grief, sadness, but also with great joy and ends with a feeling of having a new direction and perspective on life.

The Family History

Mary is a 44-year-old Caucasian mother with a four-year-old son who has a diagnosis of ASD. She has been married for 17 years and her husband, John, is 49 years old. Currently, Mary is not employed outside of the home but outwardly states that she wishes to be. She does not work due to her son's diagnosis. She has a Bachelor's degree and worked full time as an office manager until David received his diagnosis of autism. John works from home as a banker. He has an office in the basement of their home. John and Mary own their own home in an older well-kept and historical upper middle

class neighborhood. The neighborhood has schools in walking distance of the homes. Mothers are seen walking their children to school in the mornings. Their house is small and older, but has beautifully trimmed and kept gardens. This family reports an annual income of greater than \$100,000 a year. They have private health insurance. Mary described her religion as Catholic and attends church services weekly, but by herself. The family has been unable to attend church together the last couple of years because of difficulty with David's behavior related to his diagnosis of ASD.

Mary became a mom later in life. Initially, she and her husband did not want children. She enjoyed working outside of the home, gardening, and caring for this older home prior to David coming. She is organized and her home is very neat and orderly; she apologized for toys being left out when I came. She is kind, very polite, and always offers me something to drink.

Our interviews take place in her back sunroom of this restored home in the mornings after she has taken her son to school. Initially, Mary was very clinical when interviewed, but as we developed a relationship she became more open and relaxed. However, she continued to be very direct and focused when answering questions which made interviewing her easier than other mothers; she was quite articulate. During our last interview, focused on her mothering of David, she did become emotional but quickly moved on to another subject to keep herself from crying. Mary says that through her experience of mothering David, she has learned to be "the squeaky wheel" in order to get services and school support that she feels is necessary for her son. Mary has coped with and maintained control through David's diagnosis by focusing on his educational and

therapeutic needs. One of the most difficult challenges of this journey through ASD has been a loss of control. David's diagnosis has no known cause and no clear treatment or predictable outcome.

I learned about David through his mother's words during our interview. David is four years old, very verbal, and Mary describes him as "high functioning". She describes his sentences as 6-8 words long. Mary also says that David is "funny, empathetic, clever, and smart". Consistent with Mary's description of David, the DSM-oriented scales of the *Achenbach Child Behavior Checklist (CBC)*, identified David as falling into the clinical range for the following problem areas: affective, anxiety, pervasive developmental, attention deficit/hyperactivity, and oppositional defiant problems (Achenbach & Rescorla, 2000). He also fell into the clinical range for problem behaviors such as emotionally reactive, withdrawn, and attention difficulties (Achenbach & Rescorla). The *Language Development Survey* of the *Achenbach CBC* also confirmed his high verbal ability through documentation of David's large vocabulary and length of phrases in his language. Currently, David has no other medical diagnoses and sleeps fairly well.

The emotional connection between Mary and David was evident. She often spoke of how David calls her his "best friend" and that it makes her feel special and good. This bond between Mary and David is a repeating theme in her interviews. Even though she missed the opportunity to have a typically developing child, this bond is reassurance that she is being a good mother and taking good care of her son.

The “Coming” of David

Mary had an easy pregnancy with David despite him being born two and one-half weeks early. Because Mary gave birth at the age of 41, she was followed closely by her physician, but no complications arose. She had the usual fatigue and nausea, but otherwise felt well enough to continue running daily throughout the entire pregnancy. She is a petite woman, so it was no surprise that her son was delivered a little early. She also watched her weight closely throughout the pregnancy. In fact, I think Mary watched everything in her pregnancy very closely because she wanted the pregnancy to be just right.

Int: So was it a good pregnancy? Were you sick a lot?

Mary: I had an awesome pregnancy. I had nausea for a couple of weeks. I was running outside up through the end of the fifth month. I ran inside on the treadmill up until the night I gave birth.

Int: Oh my gosh.

Mary: I felt good. Fatigue was the biggest thing for me. I’m always tired anyway because I [have] low iron and all that, so I was fatigued. I had to nap every day, but we had no problems. For 40 years of age, I was very happy with that.

Int: Yeah, and running, wow. I’m feeling kind of guilty.

Mary: Well I have to admit, I was obsessed with not being fat. I’ve always had a thing about thin and being fit and I run and all that, and I was like I’m not gonna gain a lot of weight. They wanted me to gain, because I was underweight to begin with. They wanted me to gain like 35 lbs and I said no, I gained 18. The thing is about the fifth month I developed this pain that they tested and tested and couldn’t find anything wrong. The minute I started eating I got this huge pain in the upper rib cage.

Int: And it wasn’t a gall bladder issue?

Mary: They checked that, no, and every time I ate I got it, and it kept me from eating. So I just had to eat teeny, tiny portions all day long and, as much as I wanted to eat, I couldn't because of the pain. Now my first trimester, I ate everything in sight and gained six pounds... because I was just famished. Then after that I got that pain and then I couldn't eat, which I guess saved me from over indulging... but I had a very boring pregnancy. They were checking me all the time because I was so old, after 35 I think you're called high risk, but the only thing that worried her [the doctor] was this pain. Then they thought I might have gestational diabetes and I did all that series of tests.

Int: And blood pressure was fine.

Mary: Yeah.

The journey to motherhood was a long one for Mary. Initially, when they were first married, neither Mary nor her husband wanted to have children. It was not until Mary was 40 years old when she finally decided that she wanted a family. She says that her husband still was not completely on board with the decision to have a baby when David was born.

Although Mary was able to control many things during her pregnancy, such as her weight and how much she exercised, she had very little control over David's actual delivery into the world. Mary was in labor for almost 12 hours and had difficulty delivering David as he was stuck in the birth canal for almost three hours. The doctor used several different pieces of equipment in order to help deliver him. Mary has difficulty with some anesthetic agents and reacted negatively to the epidural at the end of the labor. She had such a low blood pressure that she passed out. David was born vaginally, but it was a very traumatic delivery and a scary experience. It was not at all what she had envisioned for this long-awaited child. It clearly was not the wonderful story that she imagined.

Mary: Yeah, and I always have a bad reaction to any form of anesthesia. [It's] happened every time I've had anesthesia. I crashed three times, not every time I've had anesthesia the same thing has happened, but I failed to tell my OB that. I should've told her this may happen and [to] be prepared for it. As soon as they gave [the Epinephrine] to me, I was awake and [was saying] 'what happened and where is he?' His APGAR was five and eight, so he struggled a little bit at first.

Int: So when you finally came to and you saw him, what was going through your mind?

Mary: Well, it was weird because everyone was gone except for John [my husband] and David was still in the bassinet or whatever they put him in. John's face was white and he was like... the first thing he said to me was 'if this child isn't brain damaged it will be a miracle.' That was the first thing he said to me. I was like 'is he okay?' It's like he's fine now... and I said 'I want to hold him' and so I held him... and I just started crying because it was...

Int: So emotional.

Mary: It was emotional. It was draining. I had wanted a child for 13 years and he was finally here and I crashed... it wasn't that picture perfect birth like they come out and you're like oh, put him on my stomach, let me breast feed him...

Int: I can imagine how scared your husband was seeing all of that, and then at the end you crash.

Mary: He thought he was gonna lose both of us. And just to hear him say 'if he's not brain damaged it will be a miracle', I was like oh my...so it was almost, I don't know what you call it, ironic, when he got autism. But when I held him I just started crying and John got that on camera. We have a picture of me holding him and crying because it was a 13 year wait.

Int: And was he just the most beautiful thing you've ever seen in your life?

Mary: You know, he was. You know me, being the perfectionist; he had this pointed chin, and [I said] 'what happened to his chin?' And the nurse came in and I was like 'is this permanent?' She was like he's probably going to have a pointed chin, which he doesn't now, and he had one of those red things between his eyes.

Mary's attention to details and attention to her health during her pregnancy is conflicting with her failure to inform her obstetrician of her past reactions to anesthesia. Some of this may have centered on her quest and hope for a normal delivery. Most marriages bring children and Mary and her husband had put off this decision for many years. Now that the time was here for the birth of her child, she wanted his entry into the world to be just right. She did not want to consider that complications could occur. She had focused on things she could control, such as her weight and activity level during her pregnancy, but the delivery was out of her control. Loss of control is difficult for anyone to handle, unfortunately this was going to be the start of it for Mary.

Going home was a memorable event for the family, but it was not the way that most first babies come home from the hospital. Instead of coming home to yard signs and neighbors waiting to see a new baby, there had been an ice storm and most of the neighborhood had lost power for several days. Mary was exhausted from the delivery and everything that goes with being a new mom. Her friends and family were excited and wanting to see her and the baby, but she just was not up for celebrations.

Mary: And everybody was calling, everybody was so excited, and they're like can we come and see him. I'm like 'no, I'm so tired' and then we had the ice storm moving in. I don't know if you remember the ice storm... when [the city] got hit with the ice storm and people were out of power for seven days.

Int: Oh yeah, [your city] got hit.

Mary: Yeah, so we had that to deal with. We had to get out of the hospital and get home or else we were gonna get stuck in the hospital. So we were like okay... we've got to get a generator because we [might] lose power in the wind. So we got home, it was our first night home, the ice storm hit, and all the power went off. I was watching the transformers blow down the

street and they got to ours and it stopped. We did not lose power. We were the only transformer that didn't blow on this block.

Int: Okay, so somebody was finally on your side.

Mary: I'm looking out the window going 'God, please don't do this to me, please don't do this to me' and it stopped at our neighbors house, they were the last ones to lose power.

Int: Well something worked out.

Mary: John was like this cannot be happening to me. And then everybody was wanting to come to the house... I still hadn't slept but maybe a couple of hours in three days and you're breast feeding constantly. I said to John, 'this is not what I thought it was going to be. Put a sign on the door that says please do not knock, please do not ring the doorbell, just call' and so that's what we had to do. Then after a week, I kind of got my bearings and let my family come because they were...

Int: Dying to see him.

Mary: Yes, and we had the ice storm and so they couldn't get up here. So then finally a week later the family started rolling in and it got better. I was 41 years old and had no help, my family didn't live here, it was just me and John. John took off a month, thank God, so we tag teamed, but when you're breast feeding you can't tag team. I was too tired to pump in between to build up milk for him to do the feeding, so there was not much he could do to help me.

Again, this is not what Mary envisioned for the start of her mothering experience.

She felt overwhelmed, alone, and maybe as if having this child was not the right thing to do. Many times I heard Mary reveal her age as a reason something did not work out well. Here she refers to her age as a factor of her "not so perfect" start to motherhood. Also, not only was her delivery difficult, but these difficulties followed her home through a winter storm, almost losing power, and days of exhaustion. The perfect experience had been lost.

Mary returned to work a couple months after David was born. She tried to nurse him as long as she could. She felt that this was an important mothering thing for her to do and something she was supposed to provide for him. It was difficult to do with returning to work. After six months, she could no longer juggle nursing him. She was starting to settle into a routine and things were starting to fall into place, finally.

Diagnosis Brings Marginalization

When David was nine months old, Mary started to notice that things were not quite right. She felt that his development was not on target. Mary thought back to the baby's delivery and what her husband said, "That he would be surprised if there wouldn't be something wrong" due to the traumatic nature of David's delivery into the world. Mary shared these thoughts of something not being right with several people, including her HCP, but she felt like no one listened. It was as if she was being ignored. She took David to the HCP for his nine month shots and that night David cried and screamed. Mary feels that night was the turning point and the moment that she lost her son to autism. She was unable to console David and felt she lost a connection with him then.

Mary: Between six and nine months, I started wondering then. My Parents as Teachers person, she's like... he's just delayed because he was late with all of his gross motor skills, and I started worrying. I worked with kids who had autism so I knew all the signs.

Int: Okay. So you knew a lot more. Sometimes knowledge is not a great thing.

Mary: And my parents and my family were like... you just want the perfect baby. I'm a perfectionist and you know, so he's not crawling yet, so he's not sitting up yet, [my family said] it's not a big deal. I'm like, he's not looking at me. Then after his nine month shots, between 9-12 months, we lost him. And when we went back for his twelve month shots... I just wish I hadn't done those, I said 'Doctor, there is something wrong. He's

not making eye contact. He's not trying to say mama [and] dada.' He wasn't walking; he was [only] pulling up on furniture. I said, 'everything is delayed, everything is delayed, there's something wrong.' She goes 'oh, some kids just blossom later.' I heard the same thing at 15 months... and she said let's wait three more months.

Int: Did she ever fill out the MCHAT [Modified Checklist for Autism in Toddlers]?

Mary: No.

Int: I know you filled out a thousand of these forms. She never stopped to say well here, fill this out...

Mary: The only thing she said at 15 months was if you're really concerned that he's delayed, call First Steps. So I left and I called First Steps and they were out here a couple of weeks later. They were like... he has some pretty serious delays and I'm like 'I know!' So we got started with First Steps and then a month after that I had an appointment with the neurologist. I didn't even tell my doctor [that I was going to the neurologist]... he saw him and 30 minutes later said he has autism. So I lost five months.

This passage is an example of the marginalization that Mary experienced. She had a feeling and sense that things were not right and that turned into a feeling of impending doom. One can hear the panic in her voice as she described being ignored by her son's HCP. Once again she lost the ability to maintain a sense of control; this time through silencing. A qualitative study by Minnes and Steiner that interviewed parents of children with autism in a focus group setting echoed the same problem Mary experienced; parents had brought up developmental concerns with their children up to a year prior to the HCP acknowledging and referring them for concerns of developmental delays (2009). In the end, Mary had trusted her HCP only to have those trusting instincts come back to haunt her with a diagnosis five months later. In the future, she would listen more to those instincts. Marginalization would now become an ongoing theme for future

health care experiences with this HCP. Despite being ignored by the HCP, Mary did find the strength to seek out a diagnosis for her son's delays. Receiving this diagnosis provided Mary with some validation. This validation provided the strength and confidence to continue to seek out help. This is consistent with a study conducted by Montes and Halterman which revealed that mothers of children with ASD showed remarkable strengths in coping with the adversities of having a child with autism (2007).

In hindsight, Mary's mother had suspicions as well. Rather than discussing her concerns with Mary and providing support to her daughter, her mother kept these suspicions quiet.

Mary: My pediatrician was like 'he's just slow, he'll be fine.' My dad was like 'he'll be fine.' John was like 'I don't know, I don't know as much about autism as you do. I never had a kid before, I don't know, everybody's telling us that he's fine.' My mom knew but my dad wouldn't let her tell me, because he didn't want me to be more frantic than I already was. My mom had taken care of him for three weeks... one week at 3 months, one week at 6 months, and one week at 9 months.

Int: So she had a real good gauge.

Mary: She was like... he was spinning wheels all the time, he wasn't looking at me, he wasn't responding to his name. Not so much at three months, but at six and nine she was like there's something not right. Dad was like 'don't you dare tell her because she'll be freaking out.' So when I finally got the diagnosis mom said 'I kind of suspected.'

This time it was Mary's mother that was silenced by the family. With regard to health issues, talking openly about difficult topics does not always happen in a family. It as if no one wants to say anything out loud and that ignoring the issue makes it go away. However, the cost of this denial was the loss of precious time. A qualitative study by Margetts, Le Couteur, and Croom examined the experience of grandparents who have a

grandchild diagnosed with ASD, revealing that they too experience anguish in not knowing or understanding the cause of autism (2006). Mary's parents may have been experiencing this same stress described in this study.

By 17 months, Mary had received a diagnosis of ASD from a neurologist. After the diagnosis was given to her, she was sent on her way to navigate a system that she did not understand or know anything about. Once again, Mary was marginalized by the health care system as they provided her little direction or support.

Mary: It was horrible, his bedside manners. I mean literally... I think he has Aspergers. He had no personality and he said 'yes, your son has autism. Here's a MOFEAT manual.' He gave us like 3-4 things, and of course we were just like.... Even though in my heart I knew it, [but] to actually have a neurologist thirty minutes into it say he has autism. Then he's like good luck and opened the door.

Int: So it's like he does this all day long and you're just one more person. Here it is, here's your diagnosis, get over it, here's your paper work, [and] see you later.

Mary: Yeah.

Int: Have you been back to see the neurologist?

Mary: We haven't had a reason to. He doesn't have seizures and I wouldn't go back to him anyway. I don't know if there are any good neurologists... maybe they're all a little off, maybe that's why they're neurologists. That's probably what David's going to be.

Receiving the diagnosis was difficult, upsetting, and frustrating. Mary did not feel it was delivered with empathy or respect. This was ironic to her as the very professional that diagnosed her son with a disorder characterized by an inability to have appropriate social interactions, delivered this devastating news in such a cold manner. Mary did, however, realize that the diagnosis was helpful in opening doors and receiving services, but these would be things that she would have to find and arrange for on her

own. The diagnosis was validating. It was proof that she was not crazy or imagining these things, but rather she had an understanding of her child. Even if her husband, her family, and even her son's HCP did not respect her mothering instincts, she at least now had some tangible proof that she was right and that something had been wrong.

Sharing the diagnosis with family, friends, and neighbors came quickly for Mary. She received the diagnosis just before Mother's Day and that made it even more emotional for her. Spending time with Mary made me realize that she wanted to share the information with people because she needed the support. She needed people to know that she did understand her son and that she was a good mother. She wanted them to understand more about David, the things that he did, and how this was affecting her. Her need to share in this manner was congruent with the sharing she did with me during our interviews.

Mary: I'm one of those people that can't keep that in. I can't hide it. I want everyone to know what's going on with me, because I was a wreck. They knew something was wrong. My family, I called on the phone [to tell them] because they knew we were going to this appointment. They were all eating lunch together on a Friday, for some reason, and I told my sister. I said 'he has it', and there was just silence.

Int: Yeah, because you can't say, 'oh, it will all be okay.' What do you say?

Mary: Yeah, and she was like 'well, we all knew he was going to be a special kid because he wasn't supposed to be able to happen and he happened. And now he's even more special.' I mean, she couldn't have said anything better. But we got the diagnosis two days before Mother's Day... and so I was going home to be with all the family anyway and it was just a very hard Mother's Day.

Int: What about your friends? I think you had mentioned that... your neighbors you didn't tell for a while.

Mary: The next door neighbors, who are probably our closest friends, we told immediately, because everybody in the neighborhood knew I suspected it. They

were like ‘oh, he’s fine, he’s fine, he’s fine.’ So the people I’m closest to, and [the neighbors] two houses over, we told [both of] them. And then we told [other] people as we saw them.

Int: Okay.

Mary: And for me it was a way of saying I don’t want you to look at my son and think he’s weird [because] he has autism. I’m not a bad mom, he’s not a bad kid, he has autism. And everyone was so supportive [and] they still are. I mean people get articles from the Wall Street or whatever [and] they mail it to me, [saying] ‘oh I heard about a great program’... luckily, we’re past all that now.

These developmental delays that she struggled with for many months now had a name and that gave her some confidence. But Mary was still yearning for the normalcy of motherhood and the normalcy of her child. She waited awhile to have this child and she felt that she needed people to understand that David’s autism was not her fault. Consistent with Johnston and Mash’s study on parenting satisfaction and self efficacy, Mary was evaluating her parenting ability compared to a social norm (1989). Sharing the diagnosis was a way for Mary to let others know that the behavioral and social norms for David would not be the same. It was a step toward taking more control of the situation.

There are a lot of stigmas attached to the diagnosis of autism and mothers are especially stigmatized (Gray, 2002). When a child has a behavioral outburst in public, many think that the child’s spoiled or that it is a parenting problem. One of the difficult parts of having a child with ASD is that a child with ASD does not always look outwardly disabled. Additionally, the spectrum of abilities in autism is large with some children having more deficits than others. That continues to be a struggle for Mary partly because David is typical looking, bright, and a smart child. She experiences some of this stigma because David does not “look” autistic. On the outside, he looks like every other little boy so people do not always believe that he has autism.

Mary says that even her family continued to deny the diagnosis. She says that they continued to think David's diagnosis was the result of her parenting. They blame it on her personality and refer to her as a "perfectionist".

Mary: Anyway, when I first told my family, they were in denial. They said 'no, he doesn't' so I didn't get any real support from them. They still don't think he has it [or] ever had it.

Int: Like it's a disease you catch or don't catch.

Mary: But he's just different. He's smart, that's his problem, and he's brilliant. And maybe [if] someday that's really what it turns out to be... but you don't treat it any differently. If he had social issues you treat the social issues. It doesn't matter what the label is, and that is what I was trying to get across to them. I'm not doing all of this because he has autism. I'm doing all of this because he has deficits and they just saw me as being a bad mom, putting him through heck.

Int: Still that way, or has some of that eased up?

Mary: It's gotten better because I got a third [opinion] from Dr. X, and I e-mailed them the entire report. It said in there [that] because of the early intervention, this is the way David has recovered. And I said 'please don't ever call me a bad mother again.' We saved him. We didn't hurt him. So they backed off, but I never got an apology for the things they said about me being a bad mom.

Mary does not deny that she is organized and precise, but that does not cause autism. It has been identified that mothers who had low levels of family support have significant levels of increased psychological distress (Bromley et al., 2004). This is true of Mary. In an effort to prove to her family that David truly had this diagnosis, she sought second and third opinions from other neurologists. These additional diagnoses seemed to help satisfy her family and gave Mary additional confidence. However, the hurt of being accused of not being a good mother is still there.

Mary's journey through David's diagnosis started a transformation of herself. She developed confidence and strength even as she was ignored. The diagnosis provided her with a form of validation. It showed her that her instincts were correct. As difficult as it was to receive the diagnosis, it gave Mary some sense of control over the situation. Instead of still wondering what was wrong, she was now able to focus on helping David achieve his potential. She was transforming what she thought mothering was going to be into what it would be for her.

Who is David?

One of my favorite interviews was the one focused on getting to know David through Mary's eyes. I learned that David is a child who loves letters, numbers, and to read. Although his development does not follow a typical pattern, he enjoys spending time with his friends and sharing his talents, such as reading them books since they cannot yet read. In the passage below, Mary explains how important David's friends are to him and that the hardest things for him to learn are best taught by his friends.

S: Oh, David's all about it [playing with his friends]. We tried to get him to slide for six months at the park; then one day there was an older boy who went up, came down, and David [then] went 'hmm.' He went up, came down, [and] it was over. All I needed to do was bring a neighbor kid along. So I'm thinking about doing some of those things with T-ball, maybe bring a friend.

I also learned that when David is happy, he is very happy. Those times are special to Mary. Because of his diagnosis and the therapies that accompany it, a lot of his day is spent with adults teaching him how to play, when to play, and what to play. When David gets a chance to free play and have fun, it brings a lot of joy to Mary because at

those moments, he is like other children. Seeing these times when David is happy motivates Mary to continue to focus on his education and therapies, an effort to repair what the autism has taken from his development.

Mary shared with me that one of her main wishes for David is that he be a happy child and one that has friends. She fears that people will judge him by his behavior and it will affect his ability to have a typical and fulfilled adulthood. She does not want him to be isolated and lonely. She wants him to find friendship and love as he gets older. She struggles with a balance between protecting him from the stigma of having a disability and letting him become independent.

Mary: I worry about that because he's not like the other kids.... As he gets older... he's getting closer and closer to being like the other kids. I mean he's really close. I think unless we find some other kids who are smart and quirky like he is, then he's gonna be ostracized. That's what I'm worried about.

Mary: I'm also afraid that he will never have... well, he will... I want him to have a meaningful relationship. Not only with friends but with a significant other... man, woman, whatever it is. I'll be open to whatever makes him happy. But I worry about [it]. Will he be normal enough to have a real relationship? Then I see all of these very strange people who somehow find each other in the world and I'm like... okay, if they can make it, you can find somebody.

All parents worry about their children, but David is only four and many of Mary's fears are worries about his long-term future. She also struggles with convincing herself and believing that he will be able to have a meaningful relationship as he gets older. She is afraid he will not find love, but then she convinces herself that he will, as she thinks out loud. Mary is torn between letting him grow up and protecting him from being hurt, not unlike other mothers. Having a child with a disability can exaggerate parenting. This

is because the child may be in a particular developmental stage and have a higher level of dependency for daily care for a longer period of time, therefore creating more stress and burden for the parent (Fitzgerald, Birkbeck, & Matthews, 2002). In some cases, a developmental disability may be such that the child is unable to achieve a developmental milestone. This may lead to a parent's preoccupation and intense focus on the child's developmental stages, magnifying fears for the child's future, and increasing the parent's stress level.

Health Care Provider Just Doesn't "Get It"

Taking David to the HCP is difficult, mostly because waiting for his turn is usually long. It is difficult for any child to wait a long time, but it is especially difficult for a child with ASD who not only does not have a good understanding of social cues and situations but also responds with more intensity than typically developing children. David becomes anxious when wait times become excessive. Some of this anxiety is exacerbated because Mary becomes anxious and upset during the wait. Mary admits that this does not help and that David picks up on her cues. She tries to minimize the wait time by asking to see any HCP that is available, but the office staff insists that she must see David's regular provider.

Int: All right. So you're sitting there [for the doctor] waiting, up to an hour.

Mary: The last two times we've gone, we've gone because he was sick not because it was a check up, and the first wait was 50 minutes and the last wait was an hour and 15 minutes. Both times I went to the counter and said we either need to see a doctor, I don't care who it is... and I tell them that every time, we don't have to see our normal physician for this... they all are qualified. But they insist that we see his pediatrician and I have a real problem with that. So... a lot of times I say, 'we're leaving; it's been an

hour and fifteen minutes'... and they're like, okay... so-and-so physician will fit you in. Every time I call and say 'I don't care who it is we see, I just want to get in and not wait an hour.' [They say], 'no, Dr. Q, you need to see her.'

Int: And when you go up and say I've been here a long time, it's clueless to them that David maybe can't wait that long.

Mary: It's lost on them.

Int: Okay, they don't get it.

Mary: They don't care. The girls at the front, the nurses are different, but the girls working the desk, they're herding cattle.

As Mary was telling this story, I realized that the HCP's office just does not "get it". They do not understand how difficult it is for a child with autism to wait. A health care visit is not a routine or usual event for a child with ASD, so it is confusing and anxiety provoking to wait an extended period of time in an unfamiliar setting. Mary tries to negotiate by asking to see any physician, but she is ignored and once again silenced by people who are supposed to care.

David has had many ear infections in the past. His frequent visits to the HCP for those ear infections coupled with his atypical behaviors and unusual responses to sensory experiences, that are characteristic of children with autism, may be why he is especially fearful and anxious at the HCP. Sometimes he needs to be held down for exams. Even taking his temperature using an ear thermometer causes distress for him.

Mary: We do it [practice looking at his ears] at home and he's fine, but from that moment, when they whip out the utensils his eyes get big and he's scared.... So anything associated with the ear he thinks it's painful, even when it's not. So just checking his ears... they show him the light, let him hold it, let him play with it, [and] he knows that thing's going in his ear. He's a smart kid. But he's gotten, the last few times that he's gone, [that] I'll [have to] hold him and they'll put it in his ear and he'll

kind of whimper a little bit. Then the second ear is a little bit more vocal... he just starts to flail. There was a time when we had to put him in a papoose.

David's anxiety is not limited to the HCP. He also exhibits anxiety when he has to go to the dentist, the eye doctor, when he gets his hair cut, or any activity that is out of routine. Mary has tried role playing, social stories, and practicing skills that would help him cope with these visits, but it has not helped tremendously.

Mary: It was around 12 months when everything really changed and kicked in. I mean it's the dentist, it's the eye doctor, it's the regular doctor, it's haircuts... there's just a high level of anxiety, and we don't know what caused it. He's gone so much [to the doctor], it's not like he's not exposed. We try social stories, we've tried real instruments, [in] ABA they... say aah and look in his ears. But we're like, you know, he is what he is. We can do all of this... and the minute they whip out the instruments he forgets everything. It's kind of like me and childbirth. All of that practicing breathing [and] the minute the hard labor hit, I was like give me the needle.

Mary does a lot of this with David, mixing mothering with therapy. She has taken all the forms of therapy that have been used with David in school to help him and adapted them to home situations. Applied behavior analysis (ABA) therapy looks at antecedents to behavior. She has learned to analyze each and every interaction and reaction that David has in an effort to use therapies that have worked for him in the school setting. This integration of mother and therapist role that Mary has taken on is similar to what Tsai et al. describes as integrating the nurturer-trainer roles (2008). Their qualitative study of 12 mothers of children with autism identified that a major responsibility of mothers of children with ASD was not only to provide comfort, care, and daily necessities for their child, but to also incorporate therapeutic and training activities into

all aspects of the child's daily life (Tsai et al.). The process of integration of mothering and therapy is a central struggle for Mary.

Another difficult aspect of the health care visit for Mary is that the HCP does not remember her son and his concerns, even when the information is written in the chart. She must repeat his history each time she has an appointment. Mary understands that the HCP has many patients, but her son is a patient as well.

Mary: Yeah. She [the doctor] works part time and so she has too many clients. So she's always rushed, she'll say 'good morning' but never really good morning, how are you...

Int: Right, she's just saying it because she's saying it.

Mary: Yeah. And [she asks] what's he in for today. Then she sits down. Everything is in the computer now, the little laptop, and what gets me the most is that she asks the exact same questions that she asked the last time. I've gotten to the point that I'm like if you look at your notes you'll know the answers to those questions.

Int: What kind of questions, about how he's doing over all or...

Mary: Albuterol, he used it when he was 6 months old because he had RSV. All right, every time we go in she's like, 'is he still on Albuterol?' I'm like, 'he hasn't had it since he was six months old and I tell you this every time.' That's what I did the last time. I was so aggravated by the time the wait was over, you know, and she's like, 'does he have any allergies?' [I said], 'no, it's in your records, he has no allergies to medication.' There are several questions the last time she asked [and] I'm like it's already in your notes.

Int: So she clearly doesn't remember you or remember David...

Mary: I don't even know if she remembers he has autism because he doesn't look it anymore... other than maybe on his chart it flashes autistic or whatever. But that's just this particular physician. She has too many clients, she has a child of her own who has [a disability], so she looks at David as this guy's fine. She's the same one who said he didn't have it, so I had to go over her head and find a neurologist to get the diagnosis.

What comes to my mind from this passage is that Mary does not feel as if her HCP cares enough to remember her son. A large part of pediatric health care hinges on the relationship between the patient and the provider and using a family-centered care approach. When Mary feels as if her son's HCP does not take the time to simply read what is written in his chart, she feels disregarded. Her feelings translate into anger and hostility. These types of interactions do not support the type relationship that is needed between HCP and patient and family. However, Kogan et al. found this was typical and that families with children with ASD were less likely to be satisfied with their child's health care and often did not receive family-centered care (2008).

Mary has also had a hard time developing a trusting relationship with David's regular HCP because she did not act on Mary's early concerns about David's development. The HCP told her that boys just mature more slowly. Filipek et al. showed that many parents report symptoms consistent with autism in the child's first year of life; however, a diagnosis of ASD is often not made until age three or four (1999). This is similar to what Mary experienced. Even when she insisted that something was not right, the HCP marginalized and ignored her concerns.

In contrast, another HCP in the same office does show an interest and desire to work with David and his mom. Mary shared with me how this makes her feel that this provider has a genuine concern for David; this makes her more comfortable. The concern is demonstrated in the way the HCP asks about David's needs, his development, how things are going at home, and the effort she makes to understand more about David.

It is an example of the caring interaction that can support a partnership between HCP and family.

Mary: The other one in the office that sees us when [the regular doctor] can't [because she is off] does. I want to switch to her, but she's not taking new patients and I don't know office protocol... if they would do that. It's either let me switch to her, because she understands autism [and] understands how to work with him. She asks me about his therapy... she asks me about school. She wants to know how we knew; she wants to know how I knew at six months that he had it.

Int: She's interested in learning more and working with you.

Mary: Yes. She wants to know how can we find this earlier in our other patients. Because she said most of her other patients parents are in denial, whereas I was like he has this and I want you to diagnose it. So this other doctor is completely opposite.

Int: Is he [David] any different for the other doctor that seems a little more interested, [is David] more relaxed maybe?

Mary: Mm hmm. She goes slower, and it's almost like she's had ABA. Because she's like, 'I can either check your heartbeat first or I can check your ears first, you pick'.....he feels like he has a little bit of control and he's all about control.

After receiving the diagnosis at 17 months, Mary started researching therapies, treatments, and anything she could find that might help her son. She used the internet for this process. Reading everything she could became her obsession. Kuhn and Carter's study on maternal parenting of children with autism identified that 80% of mothers felt guilt associated with not doing enough for their child with ASD (2006). Searching for therapies and treatments was a way for Mary to make sure she was doing everything she could to give David the best chance at recovery. This was also a way for her to cope with the diagnosis; she threw herself into finding a cure or treatment.

In an effort to try anything that might help David recover from his autism, Mary took him to see a Defeat Autism Now (DAN) doctor. A DAN doctor is a HCP that specializes in using alternative and biomedical treatments to treat autism. Treatments from a DAN doctor are not necessarily tested through traditional medical trials and not reimbursed by health insurance plans. Mary listened to what the DAN doctor offered, but was not interested in everything suggested. Typical of how many parents view the alternative and biomedical treatments that have been used to treat autism, she chose just a few treatments to try. Currently, David is on the gluten-free, casein-free diet and also takes vitamin supplements.

Int: Have you ever seen a DAN doctor?

Mary: Yes.

Int: Okay. How was that approach different from your regular pediatrician's approach? Was that a good experience?

Mary: No.

Int: No, okay, because they're very expensive?

Mary: They're very expensive, \$200.00 an hour. We brought David along, at her request, and we were there for at least two hours and she not once worked with him, looked at him, [or] played with him. All she did was, I felt like, she had a check list of...the things I tell all my new patients...

Int: It wasn't personalized to him.

Mary: No. I felt like she just... I go back to her once a year for B-12 that we give him. We don't give him shots, we give him pills. Anyway, the first visit was so, I don't know if she ever looked at us, she was talking above us. It's a whole different language what DAN doctors are doing. And of course my husband, who's a white paper person, [believes] if you don't have the research to prove it, I don't believe any of it. And she just talked about markers... and she left with giving us a whole bunch of

supplements and \$1000.00 later we're out the door. She wanted to do all these urine tests and hair samples and we did most of it. I was like, you know what, we'll try it and we'll spend the money. If we don't feel like it's for us we won't pursue it. So he came out of it [the autism]. I still give him 5-6 supplements. One I researched on my own, it didn't come from her, and it's helped him tremendously. But even the last time that I went, I went for a specific reason and I can't remember why. Oh, I wanted to get a letter from her about his [special] diet for his school, for his IEP.... So to do that I had to go see her, and she was trying to sell me on some piece of equipment that she invented with some person [in another city] that you just hold it and it reads the brain waves and tells you what's wrong with him. I was like really, do people buy this? So I let her do her spiel and I left and I probably won't go back.

Interestingly, even the DAN doctor, who is supposed to be well versed in working with children and families with autism, did not necessarily provide a caring and family-centered approach that Mary felt was missing from her encounters with her regular HCP. The approach that Mary experienced was cookbook. The DAN doctor even tried to exploit the family to some degree. Marginalization and being misunderstood became the premise of Mary's health care encounters.

Journey Through Motherhood...A Transformation

Mary's journey to motherhood took some time. And once she got there, it was not as she expected. It has focused on getting the right help for David. It has been a mixture of being a mother, a researcher, a doctor, a friend to David, a playmate, a therapist, a teacher, and an advocate. All of these things she has done in just a few short years when it takes most mothers a child's lifetime to encounter even some of these roles. It is as if she is in an accelerated mothering role that has been emotionally and physically exhausting.

Mary: What's weird is that I kicked into gear immediately because I knew what I had to do for him. But I couldn't accept it, the diagnosis...it

probably took a year, and at that point he was pulling out of it [the autism] so quickly I thought maybe I was wrong. But now I know... he still has a lot of the autistic traits, and I think he did have it. I think he's recovering and he'll always be quirky, he's always going to have these little nuances about him, but I was angry. I mean I think every mother goes through [this], it's a grieving process. I was sad and I was angry and beyond angry, and the whole time I never stopped working for the services. It's like that's the only thing that kept me from completely going bonkers. I'm one of those people that I can't do something 50%, I have to do 110%. I went too far probably, I probably got too many services and I was in David's face every day working with him. I quit my job and did a lot of RDI [relationship development intervention], things like that. I still do RDI with him, pulling him out of his world. I didn't just sit him in front of the TV, which would've been so much easier, and so every minute of every day I was working with him when the therapists weren't, and it just about killed me.

Int: I was going to say... are you [the] mother? [Or] are you [the] therapist?

S: I was therapist for about a year, and then when I saw that he was so much better and he just wanted a mom. And now I'm just mom and now we're attached at the hip. He goes to school and he'll tell everybody 'my mom's my best friend', you know, it's really sweet.

The grieving process is ongoing and Mary continues to mourn the loss of a typically developing child. She used her grief and anger in the most constructive way she could. She coped by focusing her energy toward obtaining services for David. Sivberg found that many parents do engage in taking an aggressive approach in obtaining services as a way of coping (2002a). Mary used this approach as a coping technique as well.

Motherhood clearly has been different than Mary expected. She envisioned that having a child would fulfill a missing piece in her life. That it would make her life more complete, but it made it more complex. Motherhood took on a complexity that was compounded by the diagnosis of autism. This was not what she bargained for. However,

it is not that her mothering experience was not fulfilling to her, but it was just different than she expected.

Mary: It's a job. I feel like his infancy, toddlerhood, and early childhood was taken away from me. It wasn't fun. We didn't do all the first time things... you know what I mean, I feel like I've been robbed. I've been cheated out of the one chance I had, and these other mom's have their challenges, especially multiple kids, but they don't have a clue at how much stress and worry goes on if you have a child with special needs. And they think they have a clue, but until you've been there.

Int: Right, you don't really get it.

Mary: You don't know. They're like, 'oh, you worry too much, oh, Mary, he's gonna be fine.' I don't know that. I just look at all these moms that take these kids to the park, they take them to church, and you know, the kids are running around chasing each other. I'm like 'oh, why couldn't that be me?'

Mary: It helps me to write them [my feelings] out. There are all these moms that say, 'oh, isn't motherhood the greatest thing ever?' And all these celebrities that say it's the best thing that ever happened to me. I'm gonna write the other book that says this sucks. Getting up every two hours is not fun, changing a diaper every hour and a half is not fun, [and] potty training is not fun. I want someone who wrote the book, that's honest, that says this is what you need to prepare for and this is how it feels and this is how you need to adapt because not every mom out there is saying oh this is the best thing I ever did. Because... right now for me, it still sucks. It's getting better. It's a lot better than it was a year ago and it's a lot better than it was the year before that, but I'm still waiting for that 'oh my gosh, this was so worth it!'

Mary feels as if she was cheated out of the complete mothering experience. Daily events and milestones that should come easily for a child are difficult for David to achieve. Each step is grueling and exhausting. Few understand it unless they have been on the journey through autism.

A daunting part of David's diagnosis was the distress Mary feels in not being able to "fix" his diagnosis. Being a good mother to Mary meant that she should be able to

solve any problem with enough effort. However, David's autism could not be resolved that easily.

Int: What's the most difficult?

Mary: Not being able to fix him. I've been, through my whole life through hard work and determination; I've been able to do whatever I wanted to do. But I can't fix him and that's the hard part for me, because I'm a problem solver.

Mary is frustrated by her inability to repair what the autism has taken from David. Since she could not fix the autism, she focused on finding therapists and treatments. The hard work and determination that solved problems for her in the past did not work this time. There were times that I felt she thought she had failed at being a mother because of this.

Mary feels like she is constantly focused on each detail of David's development. She must watch and analyze every move he makes in order to maximize his development. It is as if she takes a day off, she loses time toward making progress in closing the gap that exists in his development. This intense focus on promoting micro-steps in David's development seems to conflict with her desire to enjoy his childhood and this unique and deep bond that she has developed with him. Again, Mary is learning to integrate the roles of nurturer and therapist that are described by Tsai et al. (2008). Understanding the difficulty and time it takes to integrate and transform these roles together is an important aspect in understanding more about mothers of children with autism (Tsai et al). Mary continues to work through this transformation.

This intense focus on David's developmental milestones was bittersweet to Mary as it was also filled with joy. The positive aspect of this is that Mary had the opportunity

to appreciate each tiny milestone in a way that mothers of typically developing children may not experience. Each one became an accomplishment. She realized that she may not have noticed some of these things if it had not been for David's autism.

Int: Do you think you appreciate things more though?

Mary: Yeah.

Int: Some of the milestones and things.

Mary: I think that I do. Especially now the silver lining for me is that I never would've stayed at home and been a stay at home mom. I never would have seen him do things for the first time. We wouldn't have the bond that we have now because we do everything together. So it was a curse in one way and it was a blessing in another because unlike my other sisters, I'm getting to raise my own child and I'm getting to see every single thing he does. And I'm his best friend and he tells everybody that, 'mom is my best friend.' That's... still as hard as it is for me to deal with the autism, there is a silver lining, and I do appreciate. Oh my gosh, did you see him just go up to the other kid and say, 'hey, play with me?' Anybody else would be like, well big deal. Those are things I write in my journal. I keep a journal, so David can look back someday when I'm gone and see what we've been through with him and appreciate what we did.

As Mary spoke of relishing in these little milestones, I felt jealous. I realized that I had missed opportunities to value some of these achievements with my own typically developing children. I understood more deeply what she was saying and how treasured those moments were to her.

Autism has also brought new meaning and purpose to her life; from a focus on material accomplishments, such as her garden and her home, to an expanded definition of being a mother. She developed a deeper appreciation for people and their individuality. It forced her to slow down her life and live it.

Mary: That's it... like okay, I had to wait a while but this is my job and this is...

Int: Sort of like a calling of sorts or something like that.

Mary: Yeah, and there's not a day that goes by that I don't wish that we had been given a normal child, whatever normal is, but neurotypical. I really feel like there was a reason that David came to us and we're doing everything we can for him, and a lot of kids don't have that opportunity. Also, being a mother has made me so much less materialistic, and I've let my house go, I've let myself go, and it kind of feels nice to not be so perfectionist about everything and to just go with the flow. I've never been a go-with-the-flow kind of person, ever.

The motherhood trajectory that Mary was on when David was born was one where she was going to juggle a career with motherhood. This diagnosis allowed Mary to transform her mothering. ASD had allowed her to stay home and be more involved with David and family needs. In some ways I think she sees this as a gift. She feels a closeness and connection with David because of the diagnosis; ironic for a disorder that was once characterized as the result of the inability of a mother to bond with their child (Kanner, 1949).

Mary: I knew you were going to ask it and... I'm normally a person who likes to prepare, but I thought you know what? I'm just gonna see, because it changes for me from day to day... what it feels like to be a mother. Some days it's the best feeling in the world when I lie in bed at night and think God, what an awesome day! And then there are other nights that I'm laying in bed going, this is the biggest mistake we've ever made. Primarily because I think that had I done this ten years ago, he wouldn't have autism... that maybe my eggs would've been a little healthier. But for me, I really feel like, and this isn't pity party on me but I really had no idea why God put me here. I didn't have a career, I wasn't inventing a new vaccine, I wasn't knocking them dead in the philanthropy world, and so I always kept saying why did you put me here? I'm taking up space, that's all I'm here for. Then, after I had him I felt... okay, I have a purpose now. My goal and my purpose is to raise this child. Then to be given a child with autism, and I really feel like he was given to us, not just me, but us... because we have the determination, because we have the knowledge, and because we have resources to do everything we can for him. And so for me, being a mother, it came so late, but I finally have a reason to live.

Int: A purpose.

Mary: A purpose, that's it, not that I would not live.

As I listened to Mary talk, it was not that her life did not have a direction, but rather that she was not fulfilled in what she was doing. Mary shared with me that some of what she dreamed she would do in her life was volunteering and helping others, but that was not her husband's "dream". He was already living his dream of a quiet life in the suburbs with a neatly kept house and his career. David and his diagnosis came along and it changed. David and his diagnosis gave her a cause, a focus, and a chance to fill her need of helping others. She learned to be a strong advocate. The passion and energy she had for helping others was now going to be used. She was going to fill that void and need to "give back" by fighting David's autism.

It is evident that having a child not only changed Mary's life, but David's special needs brought richness to her life that she might not have had if David was typically developing. Her life developed more focus and meaning. She did not realize that there was an empty space until David starting filling it.

Mary: I've become a more gentle person. I stop and talk to people instead of always being in a hurry like I used to be. I always make him [David] be polite. I don't let him get away with not saying hello or not saying good-bye.

Int: He's really changed you then.

Mary: Yeah, he's calmed me down. My husband said [that] I've changed too much. I've gone too much the other way because of the way I've let the house go.

Int: Well if this is let go, then you can come to my house.

Mary: Now it's a home, whereas before it was just a house for show. Now... people feel comfortable. I think [they feel] a lot more comfortable just coming in and putting their feet up.

Int: Last question, the greatest joys of being a mom.

Mary: The greatest joys... they usually happen at night when I crawl into bed with him [David] and he puts his arms around my neck and he says, 'I had the best day ever.' I mean, I'm sure your kids have done that but it just makes it all worthwhile, because he used to not say that. And now he's a human, he's a little human, and he's like, 'I love you mom', and I'll say, 'I love you more.' And he goes, 'no, I love you the most!' I mean, those are the joys... when he really means it. When he looks at you and says I love you so much and we had such a good day.

Int: It makes it all so worth it.

Mary: Yeah, it's just like you can't replace that, you can't. Here I go crying, I'm such a woman. But the other things, the secondary things besides the love that he expresses... the fact that he worships me. I mean, I'm his best friend [and] he tells everybody that... seeing him accomplish the things I never thought he'd be able to do, like putting on his own pants, going potty and wiping himself.

As I sat listening to Mary talk about being a mother, I smiled a lot. I felt happiness for her. She has slowed down her life. She is confident, strong, and persistent. She likes the person she has become and has learned how to appreciate the little things in life more. She has made sacrifices and she is seeing the results of them in David's progress. He is developing into a compassionate and smart little boy. Mary may have taken these things for granted if she had not embarked on this journey. I think she likes who she has become and the diagnosis of autism, for all the difficulties, conflicts, and ambiguities it brings, has brought its share of gifts to her as well.

Mary's journey through motherhood was not what she expected. David's diagnosis complicated it. Along the way her family silenced her concerns and made her

feel as if she was not a good mother. She was marginalized by HCPs. Many people did not understand her need to do anything she could to help David. However, in the end, her strength and resilience persevered. This same resilience is seen in other parents who have adapted to the challenges of raising a child on the spectrum (Troy, Connolly, & Novak, 2007). Mary found joy in David's little accomplishments and that renewed her spirit.

Chapter 5: Their Voices Heard

I mean, if he has a common cold and somebody gives him an antibiotic, I can almost guarantee you he's going to be back within a week with the exact same problem. Only worse [this time] because what they gave him didn't work. His body didn't respond to the way that it [is supposed to] work and they just look at me going, 'did you give him the medicine?' 'Yes, I gave him the medicine, have you not looked at his file, do you not see all the stuff that he's been through that his body is not like everybody else.'

These are the frustrated words of Marie whose son, Mark, has autism. She is frustrated because the HCP assumes she has not followed instructions regarding the medication prescribed. However, Marie knows that her son's autism has affected his body in many ways; she does not understand why her HCP cannot see this, too.

The complexity that autism brings to caring for a child is incredible. Through the process of interviewing the mothers in this study, a deeper understanding was gained, by the researcher, about their daily experiences of raising a child with autism. The intricacies involved in simply taking a child with ASD to the HCP for a check-up requires planning that many do not understand nor can imagine. When the child is ill, it further complicates matters. This study brought forth these mothers' concerns; it gave their voices an audience so that they could be heard. The data from these mothers' interviews centered around three main themes. First, mothers expressed concern that their child's HCP and their office staff "just didn't get it." They felt that their HCPs and their office staff simply just did not understand the complexity of autism and how it affects every decision, every task, and every moment of every day. Second, HCPs often marginalized and ignored the mothers' concerns they had for their children, especially

related to development. Third, the diagnosis of ASD transformed the mothering role for these mothers in a way they did not expect. Additionally, there were general suggestions for HCPs that surfaced in the transcripts. These are referred to as “Mothers’ Pears.”

They Just Don’t “Get It”

An overwhelming concern expressed by mothers, during the health care visit interview, was a feeling that HCPs did not really understand the effects of ASD on every component of the child and the family’s lives and how difficult it is to make accommodations for a child with ASD. It was not that the HCP did not understand what autism was, but that they did not understand the deep impact of autism on every decision the mothers made and every moment of every day. If the HCPs did understand, they did not always use that knowledge to help accommodate the child in ways that either conveyed those feelings or made the mother aware of their understanding. Additionally, the provider and office staff did not always recognize the importance of tailoring the approach to care so that there was a positive outcome for the child and mother.

Several subthemes surfaced related to this feeling of not really grasping the holistic effects and complexity that autism has on the child and family. These subthemes included a need to acknowledge the expertise of the mother in working with and caring for the child, a need to recognize the emotional and physical toll of autism on the entire family, and a need to understand the mother’s need to seek out alternative therapies and treatments in an effort to help her child. The phrase “they just don’t get it” summed up the feelings of these mothers. The following subthemes will be presented via four

exemplars. The mothers that represent these exemplars include Marie, Lucy, Carrie, and Carly.

Acknowledging the Expertise of the Mother...Moms Know Best

A spectrum disorder, such as autism, necessitates a tailored approach to health care. These children have varying levels of abilities and states of health that affect the delivery of their care. Evidence shows that these children make more visits to the HCP and take more medications, thereby complicating even a simple treatment plan for a typical childhood illness (Cole, 2008). Mothers of children with ASD have recognized this, but their suggestions based on knowledge of their child was not always respected or heard by the provider.

Marie is a 30-year-old mother of Mark, who is five and getting ready to go to kindergarten next year. Marie only works occasionally on the weekends so that someone can always be home to take care of Mark. She is closely involved in every aspect of Mark's education and health care experiences. In fact, Mark's experiences with health care providers started early, as he was diagnosed with infantile spasms when he was a few months old. Throughout Mark's short 5 years, Marie has learned that Mark does not respond typically to medications. This is not unique to her son as many children with ASD experience this as well (Niehus & Lord, 2006; Volkmar et al., 2006).

Marie: I don't give him medications unless he absolutely has to have them. I mean, if he has a common cold and somebody gives him an antibiotic, I can almost guarantee you he's going to be back within a week with the exact same problem. Only worse [this time] because what they gave him didn't work. His body didn't respond to the way that it [is supposed to] work and they just look at me going, 'did you give him the

medicine?' 'Yes, I gave him the medicine, have you not looked at his file, do you not see all the stuff that he's been through that his body is not like everybody else.'

Int: So people don't get that things aren't ever typical.

Marie: No. Nobody gets that.

Int: What happens when you tell them that, do they accept that?

Marie: They look at you like that's an excuse you've just given me, like it doesn't even matter. And I've gotten aggravated with at least two of the doctors because I actually get a 'huuh' when they see my list of questions.

Marie feels frustration. She knows that her son has not reacted typically to past medications. His history of infantile spasms and diagnosis of ASD have caused him to be in and out of health care offices and the hospital since he was only a couple months old. When her son is ill and she seeks medical attention for him, she often tries to explain to the provider how he has reacted to medications and treatments in the past. However, she feels that her expertise as the mother of her child is not understood and disregarded by the HCP. She feels as if some HCP's do not want to listen to her son's history and use the information she is providing. She is not always viewed as a partner in the care of her own child. Often she is left having to take what is offered to her in the way of medication or treatments, feeling as if her HCP does not value what she knows about her son and his body. Marie's health care experiences show a lack of family-centered care. A study by Law et al. found that parents of children with disabilities were less satisfied with health care services when the approach was not family-centered (2003). This is consistent with Marie's experiences; she is left unsatisfied, frustrated, and feeling misunderstood as the mother and an expert in her own child's care.

Marie's son is also terrified of white lab coats. She has requested each time she takes him to the HCP for a visit, that the provider remove the white coat before seeing Mark because it is so upsetting for him. This simple request is not always honored or received in a positive manner.

Marie: I think the treatment was about three weeks, maybe four weeks. It was a radical treatment [ACTH injections for infantile spasms] that they did. It had a 50/50 chance of working. Thank God it worked. He hasn't had any more infantile spasms since then. But, ever since that time, if he sees a person with a white coat, I mean if we go to the pediatrician for just a well visit or if he's sick or something, I have to ask them before they go in the room 'can you please remove your coat?' If they don't and they're like 'no, he'll be all right', it's hold down, it's scream, 'no, no mommy, no, no mommy!'

Int: Are people receptive to that request to remove a white lab coat?
 Marie: No, doctors are not. And I have actually switched doctors because of that reason. I've called around. It's very hard because I know that they are doctors and they are versed in lots of different things, but when their specialty is not in autism they don't realize how [much it affects him].

Marie feels as if this is just a small request, one that can really reduce Mark's anxiety when he visits the HCP. She wishes that they would realize how making that small accommodation could improve the outcome of the visit for her son and everyone involved. She feels that if the HCP would just take an extra moment or two to recognize this uniqueness in her son, the end result of the visit would be more positive.

Some mothers felt that their HCP did not understand that the actual approach and delivery of health care services must be different for the child with ASD. Providers did not always recognize that examining a child with ASD would not ensue in the same manner that it would for a typically developing child. Again, the range of ability and disability for a child with autism can complicate the approach to care. For example,

many children with ASD have exaggerated fears or anxieties, similar to Mark's, that cause them to behave in a less than positive manner. This requires a slower and more careful, deliberate approach by the provider while the child is in the health care setting. Even though the HCP and office staff may understand what autism is and how ASD affects a child's development, several mothers felt as if the health care office staff and provider did not always grasp the necessity of this tailored approach.

Lucy's experience in taking her son, Derek, to the HCP is an example of this. Lucy has three children; Derek and his twin brother, who are three, and then an older son who is 12. She is a stay-at-home and experienced mother. She has been taking all of her children to the same HCP for many years. Lucy has been comfortable and happy with her children's HCP. However, the office staff does not really understand how to work with children with ASD, like Derek, nor do they take the time to ask her questions about the best way to meet his needs.

Lucy: They usually kind of acknowledge, like they'll talk to me, but they might say his name like 'Derek, you don't want to go back?' They'll acknowledge him, [how much] it just depends on, I guess, their mood.

Int: Do they ask you for help? Like 'what can I do' or 'do you have a suggestion?'

Lucy: No.

Int: Do they act frustrated or put off by him?

Lucy: I don't know. Sometimes I feel like they might, they're pretty regular assistants. It's like I've been going to them for a while, so sometimes you wonder what they're really thinking. Like do they wonder, 'why isn't he coming into the room?' They don't understand. You have to understand autism. He's not going to understand the concept from getting on this device [the scale] to doing my height and then to going into a room.

Even though the staff understands that he has autism, Lucy is not sure that they really understand how that affects his ability to cooperate. They expect him to get on the scale and go into the exam room like the other kids. They do not really grasp that Derek's autism affects his ability to understand the routine of the office. This becomes discouraging for her because Derek's been a patient there all his life, and they still do not understand his needs nor have they taken the time to discuss these issues with her.

Another mother, Carrie, also expresses that her son's HCP does not "get" the complexity of ASD. She is 43 years old. She quit her job, was almost finished with her graduate degree, and then she realized that she needed to be at home with Henry because of his diagnosis. Through the last couple of years, Carrie has become an advocate and parent resource for other mothers of children with ASD. She volunteers her time to help other parents who have children with ASD navigate the system. Her experiences with her son's health care office are frustrating to her.

One of the things Carrie has learned is that when her son, Henry, is ill and absent from school, his development regresses. This disruption in his school routine can take several days or even a week for him to get back on schedule. He also misses therapy when he is absent from school. These hours are not made up or replaced. Because of this, Carrie tries to be proactive and seeks help from her HCP early when her son is not feeling well. However, the HCP is not always receptive to treating Henry's illness early and aggressively. The provider often proceeds with a less aggressive approach, not fully understanding how illness affects Henry's services and routine even though Carrie has shared this with them.

Carrie: ...They're like well we have this in stock, and that's really not what you'd want to give him for this, [but] try and get as much in him as you can, etc. I usually try to get him to the doctor as soon as possible because my issue [is]... we've ended up in the emergency room a couple of times because I've said you know what... with high fevers, dehydration, etc, etc. I would rather pay the \$150 copay, go to the emergency room, bag him, put some fluids in him, get the meds in there and leave three hours later and go home and my kid be on the road to recovery...

Int: Because it's such a long road [to recovery] if you've got to do the regular or usual approach to care.

Carrie: Right, and then when my kid's out of school, he's not getting therapies and it's not like they make that up when he's gone, so I need quick treatment.

Int: And you've learned this.

Carrie: I've learned this, I have to push this.

She has learned that the more frequently Henry is ill or the longer he is ill, the harder it is for him to get back on schedule with school and therapies. When routine is disrupted for a typically developing child it is difficult; when it is disrupted for a child with autism it is even more arduous due to their developmental delays. Gains in development can be lost quickly for the child with autism when they fall out of the routine of school and therapy. Illness can complicate this further as the child who is not feeling well cannot optimally achieve his/her developmental goals and milestones.

In general, pediatrics as a specialty has a different approach; it is one that is less focused on interventions and more focused on observation and education. However, when a child with autism is ill, a more aggressive approach than usual may be necessary in order to minimize loss of therapy and subsequent losses in development. This is

something that Carrie has learned and something that her HCP may not completely understand.

Not only “getting” it, but doing it! One mother expressed that she felt her HCP did have a grasp of how autism affected the delivery of care to her son. Carly’s son, Ned, is three years old. She has another daughter who is six and typically developing. Carly has a background in counseling and was working full time until Ned’s diagnosis when she felt that she needed to be home more with him. Carly’s current HCP for her children was not her first as they recently moved. She said that she researched and talked with other mothers who had a child with ASD before she decided on her current HCP.

Carly’s current HCP demonstrates a familiarity of the intricacies and effects of autism on the child and family. This ability to grasp this and successfully accommodate and care for Ned has increased Carly’s level of comfort and trust with the HCP. Carly’s HCP acknowledged to her that developing a relationship with Ned and his mother positively impacted the health care visit. This is consistent with the recommendations from Minnes and Steiner’s study that found that it was essential to develop a good relationship between the provider, parent, and child in order to achieve quality and positive health outcomes for the child with ASD (2009). Carly and Ned benefitted from this approach from their provider.

Carly: ...As he’s standing in the corner screaming... and she was very nice. She asked ‘is he having a hard time?’ I’m like well....and she will allow time and speak to me. Giving me time to let me calm him in all of the ways I need to calm him and do all of the things I need to do as she’s speaking to me. She knows when to speak to him and when to back off, which is amazing! It’s great.

Int: I wonder how she knew to do that? She's just that good that she gets it?

Carly: I think so. I don't know what kind of experience she's had but yeah, she definitely gets it.

Carly's son is fearful of getting weighed on the scale and of getting his temperature taken; his mother recognized this as a barrier during the visit. This office routine became such a difficult obstacle and it was done each time he visited the HCP. Carly explained his fear of getting weighed to the office staff and provider several times. Finally, Carly made a suggestion that she could get Ned's weight and temperature just before she left home before Ned's appointments at the office. After discussing this with the provider, an agreement was made that this would be acceptable for Ned's visits at this office. It took several difficult visits for them to agree to this adaptation, but after the adaptation, visits started going more smoothly.

Carly: ...I had a discussion with our pediatrician because it got to the point where he just was screaming bloody murder. The scale's always in the hallway and..., really the bigger he got, it's just not going to happen. So I finally had a discussion with her and just asked if it would be okay if we did all of those things like weight and temperature at home before we came...and we try every time because I think he needs to get used to the fact that that's what we do, but I don't push it basically. She's been accepting of that. She did say sometimes we might have to do that [reweigh or take the temperature at the office], but she's been pretty good about it.

Int: Now was it you that came up with this idea?

Carly: Yeah.

Int: So she didn't really...

Carly: No, and she was a little resistant to it, but she knows him and she...it was fine.

Int: So does the person that takes you back to the room... let's say you do have to weigh him or it was one of those days when you were weighing him, is that person helping you or are they just kind of standing there expecting you to make this happen?

Carly: Usually they step back. They try to hide the fear but they're not hiding it well.

Int: Because they clearly don't know what to do or how to handle him.

Carly: They want to help, I really think they want to help, but they don't know what to do or how to do it.

Int: Have they ever asked you 'is there something I can do to help you?' or do they just kind of melt back.

Carly: No, either [they] melt back or they get a little insistent about what he needs to do, and I have to be insistent back.

Int: ... It's like they have this checklist of things.

Carly: It depends on the person but basically, yeah.

Int: And they have this routine and they don't want to bend from the routine.

Carly: Yeah, and I've gotten better about [it] up front, I'm not about the labels. I will say 'Ned has autism, the doctor and I agreed on this, it's okay for now, we're gonna try it but we're not pushing it.' At that point they're like 'okay.' I think when they hear the doctor has already heard about this and they're okay, I think they're a little more okay about it. I'm sure they still clear it with her, because I know they're concerned about his weight and how much medication he would need and that type of thing. I do understand that, and it may not be forever, and that's kind of the way I said it to the doctor, 'this might not be forever but'...

Recognizing the value of the mother's knowledge and experience with her own child and then using it as an asset in providing care is important. Children with autism are so unique with regard to fears, anxieties, and development. Listening to mothers' suggestions and taking time up front to ask for help is not just helpful but necessary when providing positive health care experiences to these children and families. Mothers want

HCPs to understand how important it is to know how to approach and care for their child with ASD. Incorporating suggestions from parents, like Carly's, reflects a true family-centered approach that involves parent and provider discussing how to achieve the best outcomes for the child (Inglese, 2009).

Not Recognizing the Emotional Toll of Autism on the Family

Another concern that became apparent was that HCPs did not understand or could not appreciate how deeply ASD affected all aspects of these mothers' lives. Kristy and Marta are two mothers who describe the day-to-day difficulties that autism imparts in their lives. Both of these mother's experiences serve as exemplars of the emotional toll that autism has on the family.

Kristy is a 28-year-old mother who is currently enrolled in nursing school. Her past medical experiences influenced her decision to pursue this career. These experiences included having another child with Down's syndrome, Marty's ASD diagnosis, and a recent miscarriage of a child with multiple anomalies. Her experience with Marty's HCP was that they had not taken the time to really consider or understand her situation and how Marty's autism impacted not only his health but also her ability to care for him. Her disappointment with this aspect of health care influenced her decision to become a nurse.

Kristy: They [health care providers] don't understand. If they knew half of what my life was like and what my son goes through every day, then they would understand. And actually, I have to credit a lot of that to nursing, because one of the things that we're learning in nursing...you can't judge somebody by their cover, because you have no idea who they are, where they were, how they got where they are, and one of the things that we've been taught [in nursing school] is that it really helps to prevent judgment

when you actually sit down and you talk to someone and you find out why they are the way they are or how they got there.

Kristy also describes how difficulties related to Marty's autism, such as his disrupted sleep pattern, affects her ability to cope with the day-to-day difficulties that autism presents. Several mothers also expressed a similar concern. Many of the HCPs were focused solely on the medical aspect of the child's health and often ignored the developmental needs of both the child and the family. However, a child's developmental needs and the family situation are also important to the child's health and the delivery of health care. Kristy felt as if the HCP did not understand that she needed help with her son's other concerns -- the concerns that were not clearly a medical problem, such as an infection or illness. She felt that if there was not a medication to prescribe to solve or cure the problem, then the provider was not interested in addressing the problem.

Kristy: I just felt like they didn't care. I felt like they simply did not care about what I was experiencing, and did not care about the fact that my child was only getting a few hours of sleep per night. To me that is not normal. To me that made things worse as far as his [Marty's] personality and temperament went, because you know, when you don't get sleep you're crabby, and when you have autism on top of that it just makes things ten times worse than they would've been. So for me, I wanted someone that was sincerely concerned with what my child was going through, and what my family was going through, and sincerely wanted to help us find a way to remedy the problem.

Marta is another mother that describes a similar concern that her HCP did not recognize how exhausting and challenging it was for her to care for her son, Leon, who has ASD. Marta is 37 years old and has two children, Leon who is four and his sister who is two. Marta works part time and stays home the other days so that she can be more available to Leon. Additionally, Marta's family is currently living with her husband's

parents so that they can take advantage of a better school system for Leon; they are trying to sell their home in the city.

At one point, Marta had a conversation with Leon's HCP that focused on taking the pacifier away from her typically developing two year old daughter. The provider was insistent that Marta wean her daughter from the pacifier as she was too old for it. Marta felt that her daughter's pacifier was the least of her everyday problems; she realized that the pacifier should be gone, but she didn't have the energy to take it away. The HCP, however, was insistent. She has so many things to deal with each day, related to Leon's autism and having another child, that the pacifier was not a priority for her and her family. Marta felt like her HCP was out of touch with the reality of her daily challenges.

Marta: I don't really think, I mean I like this doctor, but I don't think she's concerned about how anything affects us. She's been like so hard on me about this pacifier and she [her younger daughter] is only two, and she only uses it when she sleeps, but the doctor just is so psychotic about it. I'm like 'you know, we have a lot going on. My husband's in school right now, I'm in school, I work, Leon is difficult sometimes.' We have to do what's working for us right now.

Int: In the whole chain of things, the pacifier isn't really a priority...

Marta: Yeah, if she was like five I'd be like 'oh, I understand,' but she's just like well, 'you're gonna have to do it.' I think it's just very black and white [to the doctor]. If medically this is the way something is then you're just going to have to deal with it. It doesn't really matter how it affects your life.

The burden of caring for a child with ASD can be great. These mothers are under considerable stress and HCPs need to be sensitive to this level of stress (Tehee et al., 2009). Liptak, Orlando et al. found that families who felt that their HCPs did not

appreciate and understand the impact of the child's diagnosis on the function of the family had lower rates of parent satisfaction with the HCP (2006). This is consistent with the feelings of mothers in this study. They had a desire for their HCP to make an effort in understanding the entirety of their situation or to at least acknowledge their situation. They needed their child's HCP to recognize how ASD complicated even the simplest aspects of their child's health care and everyday life.

Understanding the Need to Seek Out Alternate Therapies and Treatment

The last area that mothers did not feel that HCPs understood well was the mothers' need to seek out or consider alternative therapies or treatments for their children. There was an expressed desire that the HCP have an open mind to the mothers' consideration of alternative treatments. They wanted the provider to understand and recognize the reasons why they felt compelled to consider all possible treatments; it was a way for them to do something to help their child. Nancy, Carrie, and Mary's experiences serve as exemplars for this subtheme.

Nancy is a 40-year-old mother of one child, Frank. Nancy moved to the United States a couple years ago from Puerto Rico. Her husband works in the medical field so she has some experience with and knowledge of health treatments. Nancy wanted her HCP to discuss the treatments that she had investigated on her own and was considering for her son Frank. She wanted the provider to talk about these with her with an open mind and desired the provider's expertise in discussing the benefits and possible consequences of these treatments. Nancy needed this openness so that she could make an informed decision related to the use of these treatments for her son.

Nancy: And that is why when I told you that I experienced two different doctors approach in the same office it was because of their willingness to discuss alternative treatments. Both of them are really committed and good doctors, I cannot say a bad thing at all. But one of them was more open minded.... if you [a parent] want to have an alternative approach to treating autism or try different approaches, some doctors can be a little more resistant to discussing this.

Int: So one of the doctors was... when you would bring up maybe an idea of an alternate type of therapy or something, one doctor kind of pushed you off and didn't address your concerns and one doctor was kind of 'well if you want to try it you can?'

Nancy: Exactly.

Int: With the doctor that was a little more open to it, were they educating you ... kind of helping you navigate that alternative?

Nancy: Yeah, and she did and she did with the vaccines also, so she gave me her perspective and her educated opinion and then gave me the choice to do, and I didn't feel, I didn't felt at that moment uncomfortable making either choice. That is how comfortable I feltwith the other HCP, I didn't try again, I didn't even try again.

Since there is no cure and no proven medical treatment for ASD, many mothers feel compelled to do something in an effort to try to help their child. Many parents of children with autism search the internet for information. There are also many alternative treatments and therapies on the internet that have claimed to help children with autism. Mothers did not necessarily want their HCP to recommend the use of these therapies or treatments, but rather wanted their HCP to be open enough to discuss these options with them and to understand their need to consider them. They desired their HCP provide them with information so that they could make an informed decision.

Some mothers felt that their provider was more open in discussing these treatments. This created a better relationship between provider and parent. These parents felt as if they were collaborating with the provider on issues and aspects of their child's

care that were important to them. Carrie was able to discuss the treatments that she was considering for Henry with her HCP.

Carrie: She [the pediatrician] hasn't been on board with the biomedical stuff, but she hasn't been ...oh there's a really good word to describe it. Our neurologist was more of a stinker about it than she was. She was sort of like 'hey, if you want to go see a DAN doctor okay, but now chelation no, because I think it's dangerous.' And I'm like well 'we're not doing chelation' but I wanted to look into seeing if he's got [vitamin] level issues, consider B-12 shots and zinc cream, things like that they may have some kind of help or some kind of test... I tried to get her [the pediatrician] as well as Henry's allergist and immunologist to do some of these same blood tests....Because if they ordered them it would be covered under insurance, Whereas going to the DAN doctor, it's not going to be. I'm going to have to pay out of pocket and they're expensive and they were just like what test? It's like 'okay fine' [they don't agree].

In this passage, it is evident that Carrie's need to investigate alternative treatments is not completely understood or supported by her HCP as evidenced by the providers casual way of discussing it. However, Carrie's provider does share information with her regarding the safety and efficacy of some of these treatments. So, although the HCP is not completely on board with her choice to pursue this avenue of treatment, the relationship between HCP and parent is open enough to discuss them. Even though this is not an example of a complete openness to alternative therapies, it provides an opportunity for the parent to bring up what they are considering and also gives the HCP a chance to educate them on the effectiveness or even the dangers of the treatment being considered.

In the following passage, Mary speaks of her HCP's reaction to using an alternative diet treatment, the gluten-free casein-free (GFCF) diet, for David and opting out of a recommended vaccine. You can hear Mary's worry in her words. She has been

told that there is no link between vaccines and autism, but she still is not sure and has reservations.

Mary: I think she's indifferent about the [GFCF] diet. When she wanted to give him a Hepatitis A shot, it's not a mandatory one... it's optional, a couple of different times she talked about it and I said 'I'm not giving him any more vaccines.' She's like 'you know there's no research that vaccines cause autism don't you?' She's the typical western medicine person. I said 'you know what? I understand that, but while he's in this state I'm not going to inject him with a voluntary virus.' If it's something he has to have for school I'll consider it more seriously, but if this is something that I don't have to put in him I'm not going to do it. I didn't get an eye roll, but she was pretty much [thinking] like oh, I got one of these, you know.

Int: So you could sense that she wasn't on board with that [the diet and holding on the vaccine]?

Mary: I could sense it. Now the other physician, I've never talked shots with her but she was very glad that we were doing gluten/casein free diet. She said 'you're doing everything you can to help him.'

Mary becomes defensive when she and the provider discuss these issues because she feels as if her HCP does not understand her position or point of view. She feels the provider does not "get" how difficult it is for her to still not know what caused David's autism and not having a cure or treatment for it. You can sense the friction between them; they are not working together and the basic level of understanding between the two is lacking. However, the other HCP in the office that Mary has seen openly recognizes and understands her need to exhaust all possible avenues for David's recovery. This open approach that the other provider uses provides Mary with support and understanding of her situation.

Many parents are dissatisfied with traditional treatments for autism or feel empowered by using alternative treatments for their child's autism (Hanson et al., 2007).

A study by Hanson et al. identified that 74% of families used CAM therapies; although providers may view the use of these therapies as dysfunctional, the use of them may be a unique coping mechanism for the family. No matter the reason for the consideration or use of alternative treatments, mothers clearly express a desire for HCPs to simply understand their need to consider any and all treatments when it comes to the health of their child. They desire openness in communication related to the use of these treatments.

Mothers are yearning to be understood more fully by their HCP. They want to participate actively in adapting their child's health care experiences to minimize distress and improve positive outcomes during the visit. They need their child's HCP to appreciate the stress and difficulty of daily life in caring for their child. Lastly, mothers desire an understanding and open mind to their need to consider alternative treatments. Understanding these factors can improve the provider-patient relationship in caring for not only the child with ASD, but the family as well.

Marginalized by Those Who Should Care

The second major theme that surfaced from the participants' transcripts was a marginalization or silencing of the mothers' concerns by the HCP. Mothers experienced a lack of support when they reported concerns of delayed development to their child's HCP. HCPs did not see these parent concerns as necessary to act on. Several mothers were told by the provider not to worry about delays in development since their child was a boy and boys do not mature as quickly as girls. These concerns were sometimes deferred at more than one well care visit, thereby delaying their child's diagnosis by

several months. HCPs simply provided reassurance in some cases and suggested mothers wait longer to see if the child would catch up. However, despite these reassurances, several mothers were so convinced that something was not right they sought outside evaluations and help without the knowledge or referral of their child's primary care provider. Eventually, these mothers returned to their child's provider with a diagnosis of ASD. This became a basis of distrust between HCP and mother in many cases. Some relationships between mother and provider never healed and the mothers eventually found a new HCP for their child. Marta, Jane, and Mary's experiences follow as examples of this silencing that occurred.

Marta's experience when she brought developmental concerns up to the HCP is an example of this marginalization. When Leon was about 18 months old, Marta's babysitter suggested that his development was not typical. Marta was upset and surprised by the babysitter's remarks because her HCP had never mentioned that Leon had any developmental concerns. Marta took Leon back the HCP and mentioned the babysitter's and her own concerns related to Leon's development. Rather than screening for autism or exploring Marta's concerns further, the provider simply told her to call another agency to assess Leon's development. It was not handled as a professional referral but rather a way to quietly reject Marta's concerns.

Int: So the first pediatrician you had, were they one that kind of identified that Leon was on the spectrum? Or did you have to do that yourself?

Marta: I think she was completely clueless. I mean if it weren't for a babysitter that I had then, who I was so upset with for even suggesting that maybe Leon had autism... it would've been a lot longer before we got a diagnosis. We went to the regular pediatrician and I asked her...told her

what the babysitter said. The pediatrician said, 'well yeah, I don't know, I don't really see that, but you can call Parents as Teachers' which I had already done... but she was just never [convinced]. I was wondering at the time 'do doctors not get trained in this?'....I never got copies of those developmental checklists, they just ask you each time is he doing this or is he doing that. And the talking was the big thing you know... The pediatrician would say, 'Oh well he's a boy, a lot of boys don't talk until their three,' but his delays were more than that... but she never, no, she never picked that up. And you know, with autism, the younger you get [diagnose] it, that's what's frustrating, and we were lucky because we learned about it another way.

Int: So how did she react then when you came back and ended up with a diagnosis of autism?

Marta: She said 'yeah, I had a vibe but I wasn't sure.' Then she was like 'yeah, I went to medical school with people who had autism, he'll be fine, you know.' Which hopefully he will be but, and that's good but...

Marta describes the silencing that occurred many times with mothers who have children who are later diagnosed with autism. A recent study by Rhoades et al. found that HCPs are still lacking in their ability to pick up on early developmental concerns of children (2007). This is one reason that parents are turning toward the use of outside sources, such as the internet, to learn about autism as well as using unconventional therapies for treatment (Rhoades et al.). Although HCPs are getting better with early identification, gaps still remain in knowledge related to early screening and appropriate referral for children who present with developmental delays and concerns of autism (Volkmar et al., 2006). This serves as evidence of the importance of using standardized screening forms and checklists to assist the provider in making necessary child referrals for delays.

Jane tells a similar story of marginalization when she tried desperately to get appointments with her son's HCP when she suspected developmental concerns. Jane is a

39-year-old mother of two children; her son Tim is three and has autism. Tim had his diagnosis for less than a year when she enrolled in this study. She recognized delays in communication primarily and become concerned. It took a lot of effort and persistence on her part to even get an appointment with her son's HCP to discuss these concerns. After several phone calls, she finally got an appointment to have him seen. Eventually, her concerns were heard and the HCP jumped into action, but the provider had delayed his referral by not addressing Jane's concern of Tim's language delays at 18 months. In the end, the referral was made for Tim to be seen by the neurologist; however, by then, Tim was two years old.

Int: ...Had someone told you to go to see the neurologist?

Jane: We initiated it with his primary care doctor. At the time, we were seeing another pediatrician and we had started getting increasingly more and more concerned about Tim's lack of vocalization, lack of expressing language, and I really pushed the issue with his pediatrician. In fact, we made an appointment for his sister to have her well baby checkup and.... I had called the office and said I'm getting more and more concerned about this and I really want to talk to the doctor. I didn't [get to] talk to the doctor. I just talked to, I think the receptionist, and she said 'what are your concerns?' I said, 'well he really isn't speaking a lot and I'm just really, really concerned that he's not developing the way that he should be.' She [the receptionist] said she [the pediatrician] always refers people to this particular... developmental clinic, so call and make an appointment for a speech evaluation. So I did that and they said ... the first appointment ... is like a month away, 'we'll send you some paperwork.' So I said, 'okay' and meanwhile I was kind of obsessing about this and reading a lot, and...

Int: So you kind of knew [that he had autism].

Jane: Yeah. I did kind of know ... I used to work with special needs kids. When I was in college... so I worked with a lot of autistic kids and adults who were autistic too, and I kind of knew. I had called back the pediatrician's office and said ... "can we bring T in for a separate visit around the same time [as the daughter's well check]? Like does she have anything like ½ hour before or afterwards because I really want to talk with her about this?" So when we talked

with her and met with her she immediately really got involved at that point, because she realized how concerned we were. She started just calling everybody.

Int: So she was pretty on it and very receptive to your concerns.

Jane: Yes. I think she was trying to reassure us. And we had concerns at 18 months about his lack of speech, but she was kind of like, 'well, he wasn't really talking a lot' but he was making certain vocalizations that she thought could count as words... So she wasn't that concerned at 18 months. It's a big spectrum and I think a lot of times when doctors are thinking about kids... doctors who aren't specialists, then they're thinking about kids who are autistic, they may not be visualizing the kid who's somewhere in the middle of the spectrum. They may be thinking about an extreme case and then they look at Tim and Tim will sometimes make eye contact and sometimes he can be very engaging, sometimes not so much. He does have some stereotypical behaviors but it's not like rocking back and forth.

Jane's experiences with this provider are an example of the need to understand the importance of the role of parental report in identifying developmental concerns. Jane addressed these concerns with the HCP at 18 months; however the provider did not screen Tim or act on these concerns. As Jane waited as the HCP recommended it became increasingly clear to her that Tim's communication was not improving. Eventually, after a lot of insisting and a feeling of desperation, she was listened to. Jane's experience was similar to a study conducted by Sices, Feudtner, McLaughlin, Drotar, and Williams (2004). They found that parental concern related to a child's delay was not associated with an increased likelihood of physician referral. This is interesting because conversely Boyle et al. (1996) found parental concerns to be a reliable indicator of developmental delays. Clearly, these two studies provide evidence that controversy continues to exist when it comes to understanding the role of parent report in helping the HCP determine when a referral may be necessary.

Again, Mary experienced a similar situation with David's HCP. Mary's concerns of David's developmental delays were discussed with both her family members and her HCP, both of which disregarded her concerns on more than one occasion. Her son's delays were attributed to his gender and a stereotype that boys developed and matured more slowly than girls, similar to Marta's and Jane's experiences. Unfortunately, it has been shown that gender may play an important role in a HCP's decision to refer a child with a developmental delay with girls being more readily referred for follow-up than boys (Sices et al., 2004). Eventually, Mary found the strength to seek out her own answers with regard to David's delays.

Mary: Between six and nine months... [that's when] I started wondering. My Parents as Teachers person, she said, 'he's just delayed because he was late with all of his gross motor skills' and I started worrying... and I worked with kids who had autism so I knew all the signs....Then after his nine month shots, between 9-12 months, we lost him [to autism]. And when we went back for his twelve month shots... I just wish I hadn't done those I said, 'doctor, there is something wrong. He's not making eye contact, he's not trying to say mama, dada, he wasn't walking, and he was pulling up on furniture.' I said, 'everything is delayed, everything is delayed, there's something wrong.' She goes, 'oh some kids just blossom later.' I heard the same thing at 15 months she said, 'let's wait three more months.'

Int: Did she ever fill out the MCHAT [Modified Checklist for Autism in Toddlers]?

Mary: No, the only thing she said at 15 months was if you're really concerned that he's delayed call First Steps. So I left and I called First Steps. They were out here a couple of weeks later and they were like 'he has some pretty serious delays' and I'm like, 'I know!' So we got started with First Steps and then a month after that I had an appointment with the neurologist. I didn't even tell my doctor [I was going to see a neurologist] and he [the neurologist] saw him and 30 minutes later said he has autism. So I lost five months.

Many mothers felt like their HCP was aware of autism and the signs associated with it, but they chose to take a wait-and-see approach. Several factors may be responsible for a provider's reluctance to refer a child for evaluation for concerns of autism. These factors include the limited time that providers spend with patients, limited training in identifying red flags indicative of autism, and a reluctance to raise concerns of autism due to uncomfortable feelings related to upsetting parents, and possible emotional reactions from parents (Rhoades et al., 2007). There is a need for providers to not only listen and give credibility to parent concerns, but to act on them early. Early screening and identification of ASD will provide a child with the opportunity for early enrollment into educational programs, the only established method for treating autism (Nadel & Poss, 2007).

Transformation of Their Mothering

Listening to the mothers talk, it is clear that their lives were transformed in many ways by their child's diagnosis. As difficult as it was for them to receive the diagnosis of ASD, many of them were able to find blessings and rewards from it as well. The diagnosis of a disability such as ASD brings about crisis, grief, guilt, and a feeling of loss (Briskin & Liptak, 1995). However, mothers in this study told a story of transcending these feelings and developing an inner strength to adapt their mothering roles in the face of their child's autism. Carrie, Marie, and Kristy's words will serve to describe this transformation that occurred in their mothering.

It is agreed that early intervention and therapy, for the child with ASD, is the most effective method available to treat autism (DHHS, 2008). Mothers discover this early in

the process of receiving the diagnosis for their child. This creates a feeling of urgency and the pressure of a race against time for their preschool age child to make meaningful gains in development. Mothers become intently focused on each developmental step that their child makes, monitoring their progress in detail. Carrie describes the exhaustion and guilt that ensues worrying about Henry's progress. She continually wonders if she should be doing more, as a mother, to maximize his development.

Carrie: I mean these are some very critical years that we're working with. So [I am] constantly watching that and being mindful of that, and then just the exhaustion of the emotional energy that goes into it. The guilt, the 'did I not try hard enough?' and 'am I not trying hard enough?' or 'do I need to be doing more?' That whole thing...because our society reinforces a whole martyr thing.

This intense focus and guilt that these mothers endure day in and day out is emotionally and physically draining. Kuhn and Carter found that 80% of mothers felt guilt in not doing enough for their child diagnosed with ASD. Each decision a mother makes, no matter how small or insignificant, becomes a burden for them. Working through these emotions takes strength. As the mothers move beyond receiving the diagnosis, they integrate a new way of mothering into their life. Marie describes her progression through this change in light of her current pregnancy and the apprehension she has wondering if the baby she is expecting will also have autism like Mark does.

Marie: That is probably one of the number one fears... that you're gonna do something wrong to damage them in some way. I do wonder, especially now, I do wonder if I did the right thing in letting them take him so early into school. I keep telling myself he would've been further behind if I hadn't, I have to keep reassuring myself... but yeah, it's still a constant wonder, did I do the right thing? I am especially worried now that I'm pregnant with another one. Am I going to do anything that's going to make this baby like Mark? As soon as I found out I was pregnant, I was like 'oh God, what did I do wrong to make Mark this way?'... and I know

that there is nothing I could've done that would've changed the way that he is... I guess I'm finally getting to that point where I believe that Mark is the way he is because he's supposed to be that way....

I started thinking about all the things that I ... would've never been open to. The joy and just the things that you feel [joy] over... the little things... Things that I see other parents struggling with who have kids with other special needs, and I am thankful that some of them are not as bad as Mark... and some of them are a lot worse... but I can look at a parent that is having a bad day and realize after they're stimming and they're flapping, that this child has autism. I give her a smile or a it's just it's gonna be okay [look], they do get better. I would've never, ever been open to that had I not had a son with autism, and even his health challenges that he's had ...as a baby, it would've, I don't think that I could have related to anyone in that area, because I look back at myself now, ten years later and go... man, I was a selfish brat.

Marie's transformation has moved her to a point where she able to support other parents and appreciates changes in herself that this diagnosis has brought. Although she continues to move back and forth in this process with worrying that she has made mistakes, she moves forward finding the joy in mothering her child. The transformation that she is making in herself provides her with the confidence to support other parents going through a similar situation. You can sense the satisfaction she has in who she is becoming and how she has changed; changes that would not have occurred in the same manner had Mark not been diagnosed with autism.

Carrie also describes a transformation in her mothering similar to Marie's. She realizes that Henry's little accomplishments and milestones became more meaningful to her because they were harder to come by. Therefore, these milestones became sweeter in their reward.

Carrie: Greatest joys of motherhood, oh my gosh...I think, I would divide it into two segments. Before Henry's diagnosis things were a little freer...but I was just so happy that when he was born he was healthy... and just seeing him grow and develop... and there was nothing wrong in the

world at that time, just having expectations and dreams for him, and just every little new thing he'd do every day...and then now after the diagnosis, I guess the joys from there are when I'm feeling rested and mentally stable and can look at it [the diagnosis] rationally. I can look and say, 'okay, while the data says my child hasn't made appropriate, meaningful progress in the last two years as part of his early childhood experience'... if I look back to the beginning of where he was and where he's at now and the potential I see in him regardless of that, I'm pretty proud and pretty joyful that that progress has happened. Then to see that... I think I'm pretty fortunate. I wouldn't want to trade my problems for anybody else's problems. I'll take my own, but I'm happy that even though I have a child on the spectrum, I have a child that wants... to be with us, he shows affection... even though he doesn't always get it, so being able to share in that... you look for success and ... you just look at it different. Your expectations are not lower, and I keep having to reinforce that to school and say, 'oh no, we're not lowering our expectations, he's got autism, the games not over' but you just change those expectations.

Int: So rather than getting tied up in the little things and how things are supposed to be, you appreciate the differences in your child?

Carrie: Right. Appreciate the differences and say is it really worth it and just look for that... then have expectations for him. Celebrate those [little] things because you know, as I communicate with other parents... it's like maybe to someone else with a typically developing child this wouldn't be a big deal, but to us it's a really big deal. You just have to celebrate those [little things] and that's all part of trying desperately to cope, which is it is a daily kind of struggle to be looking at your cup half full versus half empty.

Even though Carrie can see the positives in her son's development, she acknowledges the emotional and physical drain of it on a daily basis. The transformation is not complete and the journey still exists, but the progression continues to happen. The integration of what she expected out of her role as a mother and the reality of what it became were different.

Lucy feels a similar exhaustion in raising and caring for Derek. However, her exhaustion translates into some anger and resentment. Her son is younger than Carrie's and Marie's sons and, therefore, she is not as far in her transformation.

Lucy: I really despise some of my friends because they just have so much more patience and energy than me and I'm like what am I doing wrong? I wanted to have another child... It makes me feel bad, though, because I love children. I'm just so stressed out right now... I'm burnt out and I feel like I'm ashamed to tell other people that, like my friends, but I'm burnt out and they'd be like 'why?'

It is well accepted that mothers of children with ASD have high levels of stress. Specifically, Tehee et al found that parents of preschool age children with ASD receive less support than parents of older school age children with ASD (2009). This may be due to the decreased number of hours that children spend in the school setting during the preschool years compared with the school age years. Gray also noted that parent's ability to cope with autism improved as the child's age increased (2006). Gray felt that this was due to improvement in behavior and skills as the child got older. A preschool age child, typically developing or with autism, presents with greater parenting needs at these younger ages. Therefore, that may account for the increased levels of stress and exhaustion that these mothers describe.

The joyful parts of this journey through autism are described by the mothers in this study as valuing the little things in life. There is an opportunity for these mothers to enjoy and appreciate something more deeply and fully than they might have if their child had been typically developing. This ability for them to experience and appreciate these small steps in development, however, may translate into an extended and exaggerated parenting role. Mothers are essentially trapped for extended periods of time in the early

developmental stages of their children. Although this allows them to fully engage and experience each of these stages to an extreme degree, the fatigue of this adds to the complexity of the mothers' transformations. Carrie describes the emotions that accompany this journey.

Carrie: Well, I really wanted to be a mom. I mean it was a miracle we even had Henry, so I mean I love my child. Loving him is the easiest part. I won't lie and say there haven't been different parts of this journey that I have just really had feelings of resentment... because of his situation [his diagnosis] it's negatively impacted my life, my marriage... this isn't just 'oh, we will get over this' or 'I will fix this, etc.' This is a lifelong journey kind of thing... and then the fear that goes along with all the other things and the unknowns. So that has occurred and so I have resented him for that... or resented the situation because of his disability, not so much him. It's hard sometimes to separate that and I've thought 'oh my gosh, am I still being a good mom to him and having these feelings'... but you know, we work through those and they are very fleeting kind of things, but you know, I love my kid.

It is usual for mothers of children with ASD to experience the high levels of stress similar to the mothers in this study, but with that comes a resilience and strength (Montes & Halterman, 2007). Despite the unknowns attributed to the cause and developmental potential of a child with ASD, the mothers in this study were able to develop and use this strength and integrate it as they transformed into their new mothering role. Marie describes the strength she found and needed to pick up not only herself but also her husband as they move on.

Marie: We were married for five years without kids and it was hard. Then we had a child and then three years after having the child we're told that our child is not going to be like everybody else's... and that just added bricks to the load, but I think that there are ways you can deal with that. It's like 'okay, you can handle a pallet of bricks on your back or you can get a pallet jack and put them on that and you can have a wheelie and you can carry it around with you if you really want to, you know?' So yeah, it has been trying as of late, but ... just in the last couple of months I think

my husband is dealing with it a little bit more. He's getting active. He's joined Autism Speaks. He is raising money for their walk that's coming up...

Sivberg's study identified that one of the many questions parents raise when there is a child with ASD is that of the personal meaning of life (2002a). He goes on to clarify that parents who have created a meaning for their life, and not necessarily found the meaning, have a better ability to cope with their child's ASD diagnosis (Sivberg). That aspect of creating or finding a meaning to life, or in life, was the last part of the transformation witnessed in the mothers in this study. Marie and Kristy both speak to how autism has given meaning to their lives.

Marie: Totally, Mark has made me a better person than I could have ever dreamed about being. I know people that I haven't seen since high school... I have one person who probably hadn't seen me in fifteen years... come up to me and they start talking to me and they're like you're just a whole different person. I go 'it has been a long time' and he goes, 'I think it's that little boy right there.' It just brought tears to my eyes because that person understood. He understood that that's what changes you. So I think that's probably one of the best things about it.

Kristy: I just think it's a blessing. I think those of us who are parents to kids with disabilities, it's so much more special, I really do. I know a lot of parents, they say they blink their eye and their kids are grown up, and to me I think I take more of a day at a time kind of approach and appreciate every little thing, even when they're making me mad.

The process of the transformation from what the mothers expected their role to be when their child was born to what it became unfolded unexpectedly for them. The journey moved from the joy of having a child, through the difficulty of the unknown and the diagnosis, to a reintegration of their mothering role. The unexpected result for these mothers was a deep appreciation for the little things that their child did and a new creation of meaning for their own lives. Transforming through these stages to the point

of creating new meaning for their lives is evidence that they are using healthy coping strategies (Sivberg, 2002a).

Barriers to Care: Behavioral and Environmental

Through the interviews mothers' voiced both child and environmental behaviors as obstacles in the delivery of the child's health care services. Child behaviors often complicated the both the flow of the visit as well as the mothers' abilities to remember instructions provided by the HCP regarding the child's needs. Additionally, environmental barriers such as wait times and waiting room set up affected visit outcomes.

Boredom was a prevalent behavior that mothers in this study described in their children. This boredom was seen in both the waiting and the exam room. Mothers often identified both of these areas as having little available for the child to do while waiting. This translated into the child partaking in inappropriate activities, such as getting into the trash can, into cabinets, or even negative physical behaviors, such as screaming or running. The consequences to these behaviors were often the need to discipline the child as well as receiving judgmental looks and stares from other parents or office staff. Kristy describes a situation when Marty became so bored waiting to be seen that his behavior became uncontrollable.

Kristy: It's like you people [in the office] do not understand what you're doing to me. So finally we get called into this back room where they do have books... he's not really into that yet, and we waited for probably another 45 minutes before the nurse practitioner came in and Marty, the whole entire time, was hysterically out of control. I'm talking like banging his head on things, thrashing around in the stroller, screaming at the top of his lungs. [It was] so bad that it was disturbing other people in other

rooms. The nurses were coming in to check on him to make sure he was okay...

Int: So they're checking on him to see if he's okay. Are they doing anything to help you?

Kristy: No. They basically just want to make sure, I guess, that I'm not in there spanking him or something. I really don't know what they thought was going on, but the kid has been waiting for almost two hours and you think that he's just gonna sit here and be okay?

Many of the health care offices that mothers visited lacked toys or developmentally appropriate manipulative toys for the children to play with. Additionally, excessive wait times exacerbated the boredom, anxiety, and fears of the children. Mothers' ability to be patient and calm their children became difficult and added to the mothers' stresses. This increased stress also affected the mothers' ability to concentrate on the providers instructions or to even remember fully the concerns that she presented to the HCPs office with. Many mothers felt as if their HCPs office did not provide an adequate environment or the physical resources necessary to meet not only their child's needs but also typically developing children's needs.

Chapter 6: Implications for Practice

I think if I lead with the 'He has autism' it goes easier [at the office]. If I don't lead with that there's definitely a 'But this is what we do' [attitude]. So I've learned to lead with it. I normally... that was a difficult decision for me because I normally wouldn't lead with that for him, but at this point whatever makes it happen is fine, so that's where I'm at with it. I lead with it so that they kind of have an idea of what's going on.

These are Carly's words. This is how she has learned to manage each of Ned's health care experiences at his HCP's office. Even though she has taken him there many times, she continually needs to remind them that Ned has special needs. If the staff and provider do not account for this, it often prevents the experience from being a positive one for him. The fast pace of the office does not allow for the extra time that Ned needs to transition through the routine of an office visit. This is one example of why examining the barriers and resources that affect the health care experience for the child with autism is necessary.

Several practice guidelines and recommendations emerged from analyzing the data from this study. These included creating a child-family profile, understanding the transformation that mothers make during the first few years of diagnosis, and addressing environmental barriers that occur during the process of the health care visit. Incorporating these recommendations into practice provides an opportunity for HCPs to make changes in their approach that could potentially improve both the outcome of the health care visit and the partnership between family and HCP.

Creating a Child-Family Profile

Overwhelmingly, mothers in this study suggested that creating some type of profile that explained more about their child and their needs would be helpful in creating

positive health care experiences for the child and family. Development of this profile, with input from the mother or family, would provide staff and HCPs in the office a reference that would identify information necessary in working with the child. This profile would not necessarily be a medical history, but rather important information about routine and behaviors that can negatively impact the child's experience. Also, because changes in routine greatly impact the child with ASD's behavior and ability to cope, HCPs need to understand specific details about the individual needs of the child before the start of the health care visit. A profile such as this would help HCPs have a better understanding of the child and family.

The Importance of Understanding the Child's Behavior

The child's anxiety and fear, related to the health care visit, were identified as barriers in the visit by mothers in this study. Many children with ASD have higher than typical anxiety levels as a baseline (Johnson et al, 2007). These become more pronounced when the child's routine is disturbed. Young children with autism often do not understand what is going to happen when they visit the HCP; therefore, this can greatly increase their anxiety levels. Fears of the HCP also develop. Some of these fears develop from prior experiences or traumatic visits, thereby complicating future visits. However, the reasons for the child's fears are not always known. Lucy shares her experience of simply having Derek's temperature taken at the health care visit.

Int: Do they try to take his [Derek's] temperature?

Lucy: Oh yes.

Int: How do they take that?

Lucy: It's getting a little bit better now, but in the beginning it was horrible. He would just scream, and it's not the doctor that does that. It's the nurse [or] the assistant and that's where the issue comes in. Where I have to explain to them that he, with his autism, he doesn't quite understand that you need to take his temperature. We're just lifting up his arm and putting this under and you're touching his body with this thing and he's like wait a minute.

Int: And... his arm [is] held down tightly.

Lucy: And it's usually mom that's holding him down, which makes you feel lovely, but you know it has to be done, especially when he doesn't feel good. I don't even get like emotional or anything like that. It's just waiting in that room, sometimes you can wait five minutes, ten minutes, fifteen minutes, [or] twenty minutes. It's very frustrating when you have an appointment for 10:30 and you're not in there [the exam room] and the doctor's not in there at 10:30. I mean you can't do a visual picture story with your child... you get there and it's like, for Derek, he's nonverbal, he has no words.

In Lucy's situation, the longer Derek has to wait, the more anxious he becomes.

Then, as the office staff starts to take his temperature, he becomes fearful because he does not understand what they are going to do. These increased levels of anxiety and fear can manifest in behaviors such as crying, screaming, kicking, and running away for children with ASD. These behaviors become difficult to manage in the provider's office setting. Understanding more about the fears and anxieties specific to the child would help the office staff and provider plan appropriately. The ability to anticipate and plan, even a few minutes before the office visit starts, provides an opportunity to minimize fears and anxieties leading to a more positive health care experience for the child. Therefore, specific child behaviors, fears, and antecedents to negative behaviors are important to understand and should be explored with parents.

Positive Experiences from the Development of a Profile

Carrie has had experience with one of her health care providers, Henry's dentist, in developing a patient profile for Henry. This was a positive experience for both. She expressed greater satisfaction and positive outcomes with Henry's dental visits as a result of the dentist's interactions. Carrie's dentist took the time to meet with her and Henry prior to his first visit. The dentist took that time to discuss Henry's special needs and any concerns that Carrie had regarding the care Henry was to receive.

Carrie: Dr. Y is our dentist [and] he is amazing. We may have found him, you know, I think we got his card through our pediatrician. He sees a lot of kids on the spectrum. The first time I brought Henry in to see him, we actually met in his office versus like in a clinical area. Except you still walked by the chairs but they're purple and orange and yellow and fun. We met in his little office that had toys and things like that, and one of his assistants came in and asked me a bunch of questions and went over some stuff with me and then he [the dentist] came in.... He talked to us some more and then basically just had me lean Henry back on my lap onto his lap, or vice versa, and he was looking in his mouth and talking to him, so it was inside a very nice, relaxed kind of office kind of thing...

Int: So the experience was very good.

Carrie: Yeah, yeah.

Jane also had an experience where a health care provider discussed Tim's needs and the accommodations that he might need prior to coming for an office appointment. Jane had become unhappy with her HCP and looked for one that specialized in children with developmental delays. She did this because she did not feel that Tim's needs were being fully met by the prior provider. The new HCP contacted her before Tim's first appointment to complete a phone interview with her. During that interview, important information was gathered and shared between mother and this new provider. This gave

both the parent and provider an opportunity to understand more about Tim and develop a plan of care that would meet the needs of him and his family.

Jane: We were lucky. We were calling pediatricians and when I called Dr. Z's office, this was funny because I was really just calling to get Tim a well child visit so he could get his updated shots, and they asked me on the phone, "does he have any developmental disabilities?" and I said "he was just diagnosed with autism". She said "oh, the doctor will talk to you by phone before he schedules this appointment." I was like, well that's weird, and why does he need to talk to me on the phone before he can schedule Tim to get his shots? She was like well he likes to talk to all parents of kids who have developmental disabilities before they bring them in. And I was really surprised because I never had a doctor talk to me on the phone before and he [Tim] wasn't even a patient yet. He talked to me on the phone for probably about 30-45 minutes....I was like wow. So I was really lucky there too.

Both Jane and Carrie had very positive experiences when they were involved in developing a plan or profile for their sons' health care experiences. It allowed them time, outside of the health care visit, to discuss concerns and issues unique to their child in a calm and unhurried way. The ability to discuss the child and their needs in this manner gave both the provider and parent a chance to develop a collaborative relationship focused on the child's needs.

Using the parent as a consultant in developing a profile for care was recommended by Seid et al. in their study on perioperative interventions for children with autism (1997). The authors found that fostering that collaborative relationship and using the parent as a resource minimized negative outcomes for the child with ASD (Seid et al.). Additionally, the accuracy of parent's predictions regarding a child with autism's behaviors in a health care setting was supported in a study conducted by Marshall and colleagues (Marshall et al., 2008). This study used parents to predict their child's ability

to cooperate during dental procedures. The study concluded that parents not only preferred being involved in decisions regarding their child's ability to behave and cooperate during these procedures, but that parents were also accurate in predicting how their child would react and behave to specific interventions (Marshall et al.). Therefore, development of a patient specific profile for the child with ASD should be strongly considered for the general health care setting.

Developing the Profile

Several aspects should be addressed when developing this patient profile. First, the mother, or person who is the primary caregiver for the child, should be interviewed and actively involved in the development of the profile. Although this seems obvious, ample time and care should be taken in interviewing them. The profile should identify concerns that the mother has regarding their child's health. This should include both short- and long-term goals for these visits and what her desired outcomes are for the child. Many mothers in the study felt stress and anxiety over their need to "drive" the health care visit by repeating child-specific instructions and information each and every visit. Through the development of the profile, mothers will be able to provide their input up front thereby reducing their stress and the stress on the child.

Mothers also expressed a desire for their HCP to understand more about their child and their child's unique needs and abilities. It would be important to address the child's developmental level and clearly note that on the profile. Since autism is a spectrum disorder, there is a wide range of physical and psychosocial abilities. Some children are quite verbal while others may not be. It is also important to recognize and

note any specific alterations in activities of daily living for the child. For example, many children with autism have alterations in sleep and diet that affect their health status or even the mother's ability to care for them. Recognizing the family's and the child's holistic needs is essential in understanding more about the child and family.

Identifying child anxieties and fears and any antecedents to these feelings is critical in order to provide a more positive health care experience. The child's behavior as a result of these feelings should be clearly noted so that all staff and providers in the office, who are working with the child on the day of the visit, are aware of them. Many children with autism have sensory difficulties to sound, light, or touch. They may need an adapted approach to being weighed or having their temperature taken, for example. These sensory concerns, unusual fears and anxieties, and behaviors should be identified on the patient profile.

Another important piece in developing the patient profile is identifying office-related physical barriers to care. Some children are less anxious waiting in an open waiting room while others may benefit from being in a smaller area, such as the exam room. Wait times for office visits may also need to be decreased in order to optimize the child's behavior. Having a plan for these issues should be discussed early. The plan might include having the mother contact the office immediately prior to the visit to see if wait times are lengthy on that day or having the office provide an appropriate environment for the child to wait in so that anxieties and fears can be minimized.

Additionally, the patient profile should address a process for completing necessary paperwork for the health care visit. Some parents expressed that it was

beneficial for them to complete and read any necessary paperwork, such as immunization information and check-out paperwork, as soon as they arrived at the office or to have it sent to them prior to the visit. Completing paperwork either during or after the visit was difficult to juggle with their child as they were often upset from the visit. Mothers often became overwhelmed and stressed completing the paperwork. This was especially evident for the mothers that had more than one child that they had to take with them to the visit.

Discussing and understanding more about the use of any complementary and alternative treatments that mothers may be using is also important to note on the patient profile. Many parents have investigated these types of treatments in an effort to enhance their child's development or bridge gaps in their delays. HCPs need to maintain an open line of communication regarding the use of CAM in their patients. Openly asking mothers about the use of CAM will start this necessary conversation. It is important that parents and providers have the opportunity to discuss the safety and efficacy of these treatments or even the implications of a parent's desire to withhold a medically-tested intervention that there may be a misunderstanding about, such as immunizations. Mothers said they desire this open communication even when the provider does not recommend the use of CAM.

Lastly, the length of time either needed or allowed for the appointment should be discussed. HCPs see many patients during a typical day at the office. Often the parents of a child with ASD may need an extended visit length either due to child behavior or other factors that complicate the delivery of their health care. Mothers understand the

busy nature of the health care office, but often can predict when they have issues that may require more time. HCPs and parents should discuss the anticipated length of the visit up front in order to maximize the outcome for both parties. Mothers in this study clearly did not want to extend the length of time spent in the health care office on a regular basis, but recognized that there were times where they need additional time to discuss their child's health concerns.

Developing a patient profile will take additional time up front for HCPs.

However, the establishment of open communication and a desire to genuinely learn about the child and family early in the relationship and after diagnosis will be beneficial in the long run. Understanding more about the behaviors, feelings, and abilities of the child will result in a more positive health care experience for child, parent, and provider. Open communication also establishes collaboration between the patient and the provider. The spectrum of autism is wide with a range of needs and abilities. Understanding this and taking time to develop child-specific profiles will improve the delivery of care to them.

A Need to Understand the Mothering Transformation

Developing a patient profile is helpful in addressing the unique needs of the child with ASD. However, there is also a need for HCPs to understand more about the process of the mothering transformation that takes place for mothers of children with ASD. Initially, mothers are intently focused on procuring as many services as possible for their child. They feel as if they are racing against a clock to make meaningful progress in their child's development. Mothers may have feelings of guilt for not starting interventions earlier. There is also worry about decisions made and if there is enough progress toward

developmental goals. It is an intense time that is physically and emotionally draining. Davis and Carter's study of 108 parents of young children with ASD documented high levels of stress and depressive symptoms among mothers of toddlers with ASD (2008). This is consistent with the findings and words of the mothers in this study. HCPs need to be aware and understand these feelings and stress and how they may impact the child's health care visit and diagnostic process.

The mothering transformation also includes a keen appreciation of the small accomplishments of the child. Mothers cherished these achievements in developmental milestones very much. They brought a sense of satisfaction to the mothers and distinguished their mothering roles. This transcended into a new confidence and resilience that often led to a new role in advocacy for other mothers with children who had ASD. Understanding, recognizing, and appreciating these qualities in the mothers can enhance the partnership between HCP and parent, leading to more positive health care experiences for both provider and parent.

Mothers' Pearls

Environmental barriers and child behaviors during the health care visit clearly became obstacles in experiencing a positive outcome with the health care visit. Although mothers were good at packing toys and snacks for their child, having additional items in the waiting or exam rooms was one of the recommendations from mothers in this study. It was noted that offices may not have toys readily available due to concerns related to infection control. However, many mothers felt that offices should provide hand sanitizer, wipes, or clean the toys on a regular basis as it was important for the children to have

developmentally appropriate manipulatives to play with while they waited. Mothers felt this was as important for the typically developing child as it was for their child. Carrie remarked that her HCP's office used to have a large fish tank in the waiting area and that it really held her son's attention. She noted that typically developing children were also both intrigued and interested in the fish tank.

Another recommendation, or resource recommended by the mothers, was for the HCP to provide them with written instructions specific to their child's care addressed at that visit. The overwhelming nature of visit, that was often complicated with negative child behaviors due to anxiety and waiting, made it difficult for many mothers to remember the HCP's instructions. Mothers that were provided with written instructions appreciated them and used them as a reference when they returned home and had questions. Several mothers noted that having this written information saved them from calling the office back to ask about information they had forgotten.

Clearly, lengthy wait times were a concern of mothers. Several mothers had tried contacting their child's HCP's office prior to leaving for their appointment to find out if the provider was behind schedule. However, some offices would not provide them with information on the length of the wait for their HCP. Mothers' felt that this information would be helpful to receive in order to reduce their child's anxiety and boredom by reducing their wait time.

Of special note, all offices visited by the participants provided some type of reinforcement or reward at the completion of the health care visit. This was often in the

form of a sticker, piece of candy, or a small toy. All mothers remarked that this was beneficial and a practice that should continue.

Strengths and Limitations of the Study

Strengths of the Study

The methodology used was one of the strengths of this study. Using a phenomenological approach provided a deep and rich understanding of the experiences of the participants. This interpretive approach offered an opportunity to capture both descriptions and meanings of phenomena (Collingridge & Gantt, 2008). This could not have been done using quantitative research methods. Additionally, this methodology allowed for the multiple layers of meaning of these mothers' experiences to be uncovered (Smythe, Ironside, Sims, Swenson, & Spence, 2008). This interpretive phenomenological study will provide healthcare providers an opportunity to view the health care experiences of this growing population through the eyes of their patient's mother (Smythe et al.).

A second strength of this study was that it involved multiple interviews. Multiple interviews provided both an opportunity for the researcher to establish a relationship with the participant and also allowed the researcher to return and clarify information and understandings from the transcripts. Relationships were developed in initial interviews thereby deepening the depth of the later interviews. By the third interview, the richness of what many mothers were sharing was intensified. The use of field notes added to the validity of the transcripts as these notes helped verify the transcripts. These notes also

added the dimension of some immediate analysis of the interview and fresh researcher thoughts post-interview.

A third strength of this study was the planned use of several individuals reviewing and verifying the interpretation of the transcripts. Using the interpretive sessions and having other qualitative researchers review transcripts not only helped in the verification of themes, but it also helped to reduce interpretation biases that could have occurred if the researcher alone reviewed the data. The use of these interpretive sessions enhanced the rigor of the data analysis (Pohlman, 2005).

Lastly, the forestructure of the researcher proved to be an asset during the interviews. My experience in working with preschool age children with autism, as a HCP, gave me a background in the usual treatments and encounters that these children and families face. That working knowledge of resources and therapies allowed me to have a basic understanding and familiarity of their world. Having some of this basic understanding allowed me to probe and ask deeper questions during the interview.

The use of the multiple interviews, interpretive sessions, and forestructure of the researcher provided a thick and rich description of the mothers' voices. These strengths also allowed the researcher to establish credibility, transferability, dependability, and confirmability. The presence of these criterion support trustworthiness of the findings (Lincoln & Guba, 1985).

Limitations of the Study

There were several limitations of this study. The first limitation was the small sample size. Even though the sample size was small, there was some variety of ethnicity

as three mothers described their ethnicity as African American, American Indian, and Hispanic. The rest of the mothers described their ethnicity as Caucasian. Traditionally, sample sizes for interpretive phenomenology are small due to the nature of the work. The use of multiple interviews with each mother, however, helped to both strengthen and verify the data (Pohlman, 2005). Interpretive phenomenology is focused on developing a deep and rich understanding of the participant's experiences and this was achieved. With this type of work, even small sample sizes can provide understandings that are transferable. Themes that emerged from this study were important findings that will result in a greater understanding of the experiences of mothers of children with autism.

The second potential limitation was that participants were being asked to recall situations and stories. The nature of the interviews asked mothers to recall and provide stories that were retrospective and that could have led to inaccuracies. In an effort to minimize some of these effects, the researcher tried to meet with participants over a time period of several weeks in anticipation of an interview capturing a recent healthcare visit. However, only five participants had health care encounters while enrolled in the study.

A third possible limitation of the study was related to participants' possibly not fully disclosing or sharing information. In an effort to minimize this effect, the researcher planned several interviews with each mother. This was done in an effort to establish a relationship with the mothers over a period of time in order to increase their level of comfort with the researcher.

Future Opportunities for Research

Interpretive phenomenology provides a critique of instrumental reasoning and objectification. The goal is to respectfully understand the lifeworld,

critically evaluating what is oppressive, ignorant, or troublesome from the perspective of the participants and identifying sources of innovation and liberation within everyday practices. (Benner, 1994, p. 123)

This study provided a voice for a growing group of mothers who are navigating through a difficult world of health care -- a world that is unable to tell them what caused their child's autism and one that cannot tell them how to cure it. The interviews revealed important challenges that these mothers are facing in the health care system and in society in general. The information that they shared provides HCPs an opportunity to adapt the delivery of care in order to promote more positive outcomes for this population.

Interpretive research focusing on fathers of children with ASD would be important. A study focused on fathers would reveal differences or similarities in the way they cope with their child's diagnosis of autism compared with mothers. It would also increase understanding about how autism affects the fathering role and any struggles, related to the diagnosis, that are unique to fathers.

An intervention study piloting the use of patient profiles developed for the health care setting would also be useful. Although the data from this study indicate that a patient profile would be helpful in promoting a positive health care experience for both mother and child, an intervention study should be planned in order to support this. Additionally, replicating the interview focused on gathering information specific to the child's health care experience with a larger sample size might also be useful. Doing so would deepen the understanding of the findings of this study.

As Benner stated, interpretive phenomenology as a methodology can identify sources of innovation (1994). It provides a basis and the power to effect changes in

practices through the voices of the participants (Benner, 1994). This study opened the door and enlightened the understanding of the experiences of these mothers. Continued work on this research trajectory will provide more opportunities to affect and promote the delivery of health care for this population.

Reflections of the Researcher

My experience of interviewing these 11 mothers was more relaxed and pleasant than I expected. They were eager to share their stories and readily scheduled subsequent interviews. They made me feel at ease as they discussed their journeys and experiences of being a mother of a child with autism. The relationship that I developed with each of the mothers made it difficult to end the study, especially the richness of the encounter of our last interview on mothering. Almost every final interview ended with sadness, from both parties, that our relationship could not continue. These mothers shared many very personal examples of feelings of loss and guilt when they received their child's diagnosis. The joys, however, that they expressed as their children achieved each small milestone in development were uplifting. It made me realize that, as a mother of typically developing children, I may not have always appreciated my own children's accomplishments as I should have. The courage, strength and resilience these mothers exhibited was inspiring. Their example of mothering will always impact me personally and professionally. I cannot thank them enough for sharing their experiences and journey with me.

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Appendix A

Demographic Questionnaire

ID _____

Age: _____

How would you describe your ethnicity? _____

What is the highest level of education obtained?

_____ Less than High School

_____ High School Diploma/GED

_____ Vocational School

_____ Associate Degree

_____ Bachelors Degree

_____ Graduate Degree

_____ Other, Specify: _____

How would you describe your marital status? _____

How long? _____

How many children do you have? _____

What are their ages? _____

Spouse/Significant Other Age: _____

Have you been married before? _____

Are you presently employed outside the home? _____

If yes, how many hours? _____

What is your occupation? _____

Is your significant other/spouse employed outside the home? _____

How many hours a week? _____

What is their occupation? _____

What is your yearly household income?

Less than \$20,000 _____

\$21,000-\$60,000 _____

\$61,000-\$100,000 _____

Greater than \$100,000 _____

Does your child have health insurance? _____

What type? _____

Do you rent or own your home? _____

What is your religion? _____

Do you attend church, how often? _____

Appendix B

Please print. Be sure to answer all items.			CHILD BEHAVIOR CHECKLIST FOR AGES 1½-5			For office use only ID# _____	
CHILD'S FULL NAME: First _____ Middle _____ Last _____						PARENTS' USUAL TYPE OF WORK, even if not working now. Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant. _____	
CHILD'S GENDER <input type="checkbox"/> Boy <input type="checkbox"/> Girl		CHILD'S AGE _____		CHILD'S ETHNIC GROUP OR RACE _____		FATHER'S TYPE OF WORK _____ MOTHER'S TYPE OF WORK _____	
TODAY'S DATE Mo. _____ Day _____ Year _____				CHILD'S BIRTHDATE Mo. _____ Day _____ Year _____		THIS FORM FILLED OUT BY: (print your full name) _____	
Please fill out this form to reflect <i>your</i> view of the child's behavior even if other people might not agree. Feel free to write additional comments beside each item and in the space provided on page 2. Be sure to answer all items.						Your relationship to child: <input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Other (specify): _____	

Below is a list of items that describe children. For each item that describes the child **now or within the past 2 months**, please circle the **2** if the item is **very true or often true** of the child. Circle the **1** if the item is **somewhat or sometimes true** of the child. If the item is **not true** of the child, circle the **0**. Please answer all items as well as you can, even if some do not seem to apply to the child.

	0 = Not True (as far as you know)	1 = Somewhat or Sometimes True	2 = Very True or Often True	
0 1 2				1. Aches or pains (without medical cause; do not include stomach or headaches)
0 1 2				2. Acts too young for age
0 1 2				3. Afraid to try new things
0 1 2				4. Avoids looking others in the eye
0 1 2				5. Can't concentrate, can't pay attention for long
0 1 2				6. Can't sit still, restless, or hyperactive
0 1 2				7. Can't stand having things out of place
0 1 2				8. Can't stand waiting; wants everything now
0 1 2				9. Chews on things that aren't edible
0 1 2				10. Clings to adults or too dependent
0 1 2				11. Constantly seeks help
0 1 2				12. Constipated, doesn't move bowels (when not sick)
0 1 2				13. Cries a lot
0 1 2				14. Cruel to animals
0 1 2				15. Defiant
0 1 2				16. Demands must be met immediately
0 1 2				17. Destroys his/her own things
0 1 2				18. Destroys things belonging to his/her family or other children
0 1 2				19. Diarrhea or loose bowels (when not sick)
0 1 2				20. Disobedient
0 1 2				21. Disturbed by any change in routine
0 1 2				22. Doesn't want to sleep alone
0 1 2				23. Doesn't answer when people talk to him/her
0 1 2				24. Doesn't eat well (describe): _____
0 1 2				25. Doesn't get along with other children
0 1 2				26. Doesn't know how to have fun; acts like a little adult
0 1 2				27. Doesn't seem to feel guilty after misbehaving
0 1 2				28. Doesn't want to go out of home
0 1 2				29. Easily frustrated
0 1 2				30. Easily jealous
0 1 2				31. Eats or drinks things that are not food— don't include sweets (describe): _____
0 1 2				32. Fears certain animals, situations, or places (describe): _____
0 1 2				33. Feelings are easily hurt
0 1 2				34. Gets hurt a lot, accident-prone
0 1 2				35. Gets in many fights
0 1 2				36. Gets into everything
0 1 2				37. Gets too upset when separated from parents
0 1 2				38. Has trouble getting to sleep
0 1 2				39. Headaches (without medical cause)
0 1 2				40. Hits others
0 1 2				41. Holds his/her breath
0 1 2				42. Hurts animals or people without meaning to
0 1 2				43. Looks unhappy without good reason
0 1 2				44. Angry moods
0 1 2				45. Nausea, feels sick (without medical cause)
0 1 2				46. Nervous movements or twitching (describe): _____
0 1 2				47. Nervous, highstrung, or tense
0 1 2				48. Nightmares
0 1 2				49. Overeating
0 1 2				50. Overtired
0 1 2				51. Shows panic for no good reason
0 1 2				52. Painful bowel movements (without medical cause)
0 1 2				53. Physically attacks people
0 1 2				54. Picks nose, skin, or other parts of body (describe): _____

Be sure you answered all items. Then see other side.

Please print your answers. Be sure to answer all items.

0 = Not True (as far as you know)			1 = Somewhat or Sometimes True			2 = Very True or Often True		
0	1	2	55. Plays with own sex parts too much	0	1	2	79. Rapid shifts between sadness and excitement	
0	1	2	56. Poorly coordinated or clumsy	0	1	2	80. Strange behavior (describe): _____	
0	1	2	57. Problems with eyes (without medical cause) (describe): _____	0	1	2	81. Stubborn, sullen, or irritable	
0	1	2	58. Punishment doesn't change his/her behavior	0	1	2	82. Sudden changes in mood or feelings	
0	1	2	59. Quickly shifts from one activity to another	0	1	2	83. Sulks a lot	
0	1	2	60. Rashes or other skin problems (without medical cause)	0	1	2	84. Talks or cries out in sleep	
0	1	2	61. Refuses to eat	0	1	2	85. Temper tantrums or hot temper	
0	1	2	62. Refuses to play active games	0	1	2	86. Too concerned with neatness or cleanliness	
0	1	2	63. Repeatedly rocks head or body	0	1	2	87. Too fearful or anxious	
0	1	2	64. Resists going to bed at night	0	1	2	88. Uncooperative	
0	1	2	65. Resists toilet training (describe): _____	0	1	2	89. Underactive, slow moving, or lacks energy	
0	1	2	66. Screams a lot	0	1	2	90. Unhappy, sad, or depressed	
0	1	2	67. Seems unresponsive to affection	0	1	2	91. Unusually loud	
0	1	2	68. Self-conscious or easily embarrassed	0	1	2	92. Upset by new people or situations (describe): _____	
0	1	2	69. Selfish or won't share	0	1	2	93. Vomiting, throwing up (without medical cause)	
0	1	2	70. Shows little affection toward people	0	1	2	94. Wakes up often at night	
0	1	2	71. Shows little interest in things around him/her	0	1	2	95. Wanders away	
0	1	2	72. Shows too little fear of getting hurt	0	1	2	96. Wants a lot of attention	
0	1	2	73. Too shy or timid	0	1	2	97. Whining	
0	1	2	74. Sleeps less than most kids during day and/or night (describe): _____	0	1	2	98. Withdrawn, doesn't get involved with others	
0	1	2	75. Smears or plays with bowel movements	0	1	2	99. Worries	
0	1	2	76. Speech problem (describe): _____	0	1	2	100. Please write in any problems the child has that were not listed above.	
0	1	2	77. Stares into space or seems preoccupied	0	1	2		
0	1	2	78. Stomachaches or cramps (without medical cause)	0	1	2		

*Please be sure you have answered all items.
Underline any you are concerned about.*

Does the child have any illness or disability (either physical or mental)?

☐ No

☐ Yes—Please describe:

What concerns you most about the child?

Please describe the best things about the child:

LANGUAGE DEVELOPMENT SURVEY FOR AGES 18-35 MONTHS

For office use only
ID #

The Language Development Survey assesses children's word combinations and vocabulary. By carefully completing the Language Development Survey, you can help us obtain an accurate picture of your child's developing language. *Please print your answers. Be sure to answer all items.*

- I. Was your child born earlier than the usual 9 months after conception?
☐ No ☐ Yes—how many weeks early? _____ weeks early.
- II. How much did your child weigh at birth? _____ pounds _____ ounces; or _____ grams.
- III. How many ear infections did your child have before age 24 months?
☐ 0-2 ☐ 3-5 ☐ 6-8 ☐ 9 or more
- IV. Is any language beside English spoken in your home?
☐ No ☐ Yes—please list the languages: _____

- V. Has anyone in your family been slow in learning to talk?
☐ No ☐ Yes—please list their relationships to your child; for example, brother, father:

- VI. Are you worried about your child's language development?
☐ No ☐ Yes—why? _____

- VII. Does your child spontaneously say words in any language? (not just imitates or understands words)?
☐ No ☐ Yes—if yes, please complete item VIII and page 4.
- VIII. Does your child combine 2 or more words into phrases? For example: "more cookie," "car bye-bye."
☐ No ☐ Yes—please print 5 of your child's longest and best phrases or sentences.
 For each phrase that is not in English, print the name of the language.
1. _____
 2. _____
 3. _____
 4. _____
 5. _____

Be sure you have answered all items. Then see other side.

Please circle each word that your child says SPONTANEOUSLY (not just imitates or understands). If your child says non-English versions of words on the list, circle the English word and write the first letter of the language (e.g., S for Spanish). Please include words even if they are not pronounced clearly or are in "baby talk" (for example: "baba" for bottle).

FOODS	ANIMALS	ACTIONS	HOUSEHOLD	MODIFIERS	OTHER
1. apple	55. bear	107. bath	163. bathtub	216. all gone	264. any letter
2. banana	56. bee	108. breakfast	164. bed	217. all right	265. away
3. bread	57. bird	109. bring	165. blanket	218. bad	266. booby
4. butter	58. bug	110. catch	166. bottle	219. big	267. byebye
5. cake	59. bunny	111. clap	167. bowl	220. black	268. excuse me
6. candy	60. cat	112. close	168. chair	221. blue	269. here
7. cereal	61. chicken	113. come	169. clock	222. broken	270. hi, hello
8. cheese	62. cow	114. cough	170. crib	223. clean	271. in
9. coffee	63. dog	115. cut	171. cup	224. cold	272. me
10. cookie	64. duck	116. dance	172. door	225. dark	273. meow
11. crackers	65. elephant	117. dinner	173. floor	226. dirty	274. my
12. drink	66. fish	118. doodoo	174. fork	227. dry	275. myself
13. egg	67. frog	119. down	175. glass	228. good	276. nighttime
14. food	68. horse	120. eat	176. knife	229. happy	277. no
15. grapes	69. monkey	121. feed	177. light	230. heavy	278. off
16. gum	70. pig	122. finish	178. mirror	231. hot	279. on
17. hamburger	71. puppy	123. fix	179. pillow	232. hungry	280. out
18. hotdog	72. snake	124. get	180. plate	233. little	281. please
19. ice cream	73. tiger	125. give	181. potty	234. mine	282. Sesame St.
20. juice	74. turkey	126. go	182. radio	235. more	283. shut up
21. meat	75. turtle	127. have	183. room	236. nice	284. thank you
22. milk		128. help	184. sink	237. pretty	285. there
23. orange	BODY PARTS	129. hit	185. soap	238. red	286. under
24. pizza	76. arm	130. hug	186. spoon	239. stinky	287. welcome
25. pretzel	77. belly button	131. jump	187. stairs	240. that	288. what
26. raisins	78. bottom	132. kick	188. table	241. this	289. where
27. soda	79. chin	133. kiss	189. telephone	242. tired	290. why
28. soup	80. ear	134. knock	190. towel	243. wet	291. woofwoof
29. spaghetti	81. elbow	135. look	191. trash	244. white	292. yes
30. tea	82. eye	136. love	192. T.V.	245. yellow	293. you
31. toast	83. face	137. lunch	193. window	246. yucky	294. yumyum
32. water	84. finger	138. make			295. any number
	85. foot	139. nap	PERSONAL	CLOTHES	PEOPLE
TOYS	86. hair	140. open	194. brush	247. belt	296. aunt
33. ball	87. hand	141. outside	195. comb	248. boots	297. baby
34. balloon	88. knee	142. patty cake	196. glasses	249. coat	298. boy
35. blocks	89. leg	143. peekaboo	197. key	250. diaper	299. daddy
36. book	90. mouth	144. peepee	198. money	251. dress	300. doctor
37. crayons	91. neck	145. push	199. paper	252. gloves	301. girl
38. doll	92. nose	146. read	200. pen	253. hat	302. grandma
39. picture	93. teeth	147. ride	201. pencil	254. jacket	303. grandpa
40. present	94. thumb	148. run	202. penny	255. mittens	304. lady
41. slide	95. toe	149. see	203. pocketbook	256. pajamas	305. man
42. swing	96. tummy	150. show	204. tissue	257. pants	306. mommy
43. teddy bear		151. shut	205. tooth brush	258. shirt	307. own name
	VEHICLES	152. sing	206. umbrella	259. shoes	308. pet name
OUTDOORS	97. bike	153. sit	207. watch	260. slippers	309. uncle
44. flower	98. boat	154. sleep		261. sneakers	310. name of TV
45. house	99. bus	155. stop	PLACES	262. socks	or story
46. moon	100. car	156. take	208. church	263. sweater	character
47. rain	101. motorcycle	157. throw	209. home		
48. sidewalk	102. plane	158. tickle	210. hospital		
49. sky	103. stroller	159. up	211. library		
50. snow	104. train	160. walk	212. park		
51. star	105. trolley	161. want	213. school		
52. street	106. truck	162. wash	214. store		
53. sun			215. zoo		
54. tree					

Other words your child says, including non-English words:

Appendix C

Health Care Visit Coping Interview Guide

Adapted from Lazarus and Folkman (1984) and Pohlman (2003)

I am interested in learning more about what happens when you take your child to the health care provider.

This guide will be adapted depending on the timing of the child's health care visits

A. Can you tell me what happens when you take your child to visit the health care provider?

Prompts:

1. Why do you usually visit the health care provider?
2. Does your child have any other health diagnoses?
 - a. Tell me about those.
3. How do you know when your child is sick or needs to go to the health care provider?
4. Where are some of the places you get health information from?
5. Tell me about your child's health care provider?
 - a. How does your child react when the provider walks in the room?
 - b. How does the health provider make you feel?
6. Do you feel like your child's needs are addressed when you take him/her to the health care provider?
 - a. Are your needs, as a mother, addressed? Explain
 - b. What are some barriers to meeting these needs?
 - c. What are some resources that help those needs get met?
 - d. Who or what is most helpful during the visit?
7. What are your thoughts, feelings and reactions when you know you have to take your child to the health care provider?
 - a. What about after the visit?
8. Describe your child's actions, responses, to health care visits.
9. Did you consider any alternatives to making a health care visit?
10. What have you learned about your health care provider over time?
11. Is there anything more that I haven't covered?

For first interview only (parts B and C):

B. Can you tell me about a health care visit (for your child) that was particularly satisfying and meaningful to you?

Prompts:

1. Tell me what happened.
2. What lead up to this visit?
3. What were your thoughts and feelings about the visit?
4. Why were these feelings different from previous situations you have had with your child?
5. Did you take any action in this visit? What was it?
6. Did you learn anything new in this situation about yourself?
 - a. Anything new about your child?
7. Was anyone else involved in the situation?
 - a. How were they helpful?
 - b. How were they a hindrance?
8. Is there anything else about this situation that you think I should know about or something I did not cover?

C. Can you tell me about a health care visit (for your child) that was particularly difficult for you and your child?

Prompts:

1. Tell me what happened.
2. What lead up to this visit?
3. What were your thoughts and feelings about the visit?
4. Why were these feelings different from previous situations you have had with your child?
5. Did you take any action in this visit? What was it?
6. Did you learn anything new in this situation about yourself?
 - a. Anything new about your child?

7. Was anyone else involved in the situation?
 - a. How were they helpful?
 - b. How were they a hindrance?
8. Is there anything else about this situation that you think I should know about or something I did not cover?

For additional health care encounters during enrollment in the study use section D

D. Can you tell me about the most recent visit to the health care provider?

Prompts:

1. Tell me what happened.
2. Why was the visit made?
3. What were your thoughts, feelings and reactions to the situation? What were the priorities during the visit?
4. Describe what happened during the visit.
5. Describe your child's actions, responses, to the visit.

Prompts:

- a. What happened when you got there?
 - b. What happened while you were waiting to see the provider?
 - c. What happened during the visit?
 - d. What happened when you left?
6. Tell me about your interaction with the Health Care Provider.
7. Tell me about your child's interactions with the Health Care Provider.
8. How did you feel afterwards?
9. Did you consider any alternatives to making a health care visit?
10. Where there any "barriers" during this visit?
11. Where there any "resources" that helped during this visit?
 - a. Who or what was most helpful to you during this visit?
12. Looking back now, would you do anything different?
13. What did you learn about yourself during this visit?

14. What did you learn about your child during this visit?
15. What did you learn about your health care provider during this visit?
16. Is there anything more about the visit that I haven't covered?

Appendix D

Understanding Mothering the Child with Autism Interview Guide

I would like to understand more about what it is like having a child diagnosed with Autism.

Prompts:

1. Tell me about your pregnancy with your child.
2. What were your feelings, thoughts, and reactions when your child was first born?
3. When was one of the first times you thought that something may not be typical or right?
 - a. What was going on (in your life) during that time?
 - b. Did you share your feelings with anyone?
4. Describe the situation or the time when you first were told that your child had Autism.
 - a. Where were you?
 - b. Who gave you the information?
 - c. Describe how you felt.
5. How did you tell your family and friends about your child's diagnosis?
6. How has this changed you as a person? A mother?
7. How do you think mothering a child with Autism is different than mothering a typically developing child?
8. Is there anything else you would like to say about your experience mothering a child with Autism?

Appendix E

Understanding Your Child with Autism Interview Guide

I would like to understand more about your child with Autism.

1. Tell me about your child.

Prompts:

- a. What is your child's favorite thing to do?
- b. What is your child's least desired thing to do?
- c. Describe a situation when your child was very happy.
- d. Describe a situation when your child was not happy.
- e. What do you wish most for your child?
- f. How does your child react to unfamiliar situations?
 - i. Familiar situations?
- g. What are your child's greatest gifts?
- h. Describe how you know when your child is happy.
- i. Describe how you know when your child is upset.
 - i. Hurt.
 - ii. Sad.
 - iii. Angry.

2. Describe any health problems your child has.

Prompts:

- a. What health care providers does your child visit?
- b. Does your child have any other medical diagnoses?
 - i. What are they?
- c. Does your child take any regular medications?
 - i. What are they and what are they used for?

3. Describe your child's behavior.

Prompts:

- a. Describe his/her behavior at home.
- b. Describe his/her behavior at school.
- c. How does your child behave differently for different people?
 - i. Describe these differences.

4. Describe how your child interacts within your family.

5. Do you think there were any particular things that lead to your child's autism?

Appendix F

Meanings of Motherhood Interview Guide
Adapted from Pohlman (2003) and (SmithBattle, 1992)

I would like to know more about what it is like for you to be a mother.

1. What is it like being a mother?
2. What aspects of being a mother are the most surprising?
 - a. Most difficult?
 - b. Easiest?
3. Tell me about your mother.
 - a. Do you think your mother was a good mother to you while you were growing up?
 - b. What was she like?
 - c. What did she do for a living? Work at home or outside the home?
4. Describe a situation that reflects for you how you were cared for by your parents?
5. Are there things that you want to convey to your children that your mother passed on to you?
6. Is there anyone that stands out in your mind that is a particularly good mother?
 - a. Tell me about them.
7. Is there anyone that stands out in your mind that is a particularly bad mother?
 - a. Tell me about them.
8. What is most important to you in raising your child?
9. What fears and/or concerns do you have for your child?
10. What fears and/or concerns do you have about being a mother?
11. How satisfied are you with your marriage/relationship?
 - a. Can you talk to your partner/spouse about your feelings?
12. What do you think a mother is supposed to be and do?
13. What are the greatest joys of motherhood for you?

Appendix G

Summary of Mothers Enrolled in the Study

Mother	Child	Demographic Information	Family Information	Child Information
Mary, 44 years old	David, 4 years old	Caucasian Bachelor Degree >\$100,000/yr	Married 17 years. Mary worked full time prior to David's diagnosis and has since stayed home. Her husband works from home.	David is an only child. He has no other medical concerns.
Marie, 30 years old	Mark, 5 years old	American Indian High School/GED \$21-60,000/yr	Married 10 years. Currently pregnant. Stays at home with Mark, but contracts to work odd jobs selling products for various companies. Marie's mother has been a foster mother to several children over the years.	Mark was born full term but developed infantile spasms at a few months of age. He had extensive visits to the HCP for treatment for these. These have been resolved for about 4 years now.
Lucy, 40 years old	Derek, 3 years old	Caucasian High School/GED <\$20,000/yr	Married 6 years and has 3 children ages 12, 3, and 3. Her oldest son was from a prior marriage. She stays at home.	Derek has a twin brother who does not have autism. He has no significant medical history.
Carrie, 43 years old	Henry, almost 5 years old	Caucasian Bachelor Degree, almost finish with Graduate degree and stopped. >\$100,000/yr now	Married 8 years. Carrie was working full time and finishing graduate school when she quit work to stay home full time with Henry. Her husband was unemployed for a year and just recently returned to work.	Henry has no other medical diagnoses. He is their first and likely only child as he was difficult to conceive.

Mother	Child	Demographic Information	Family Information	Child Information
Carly, 37 years old	Ned, 3 years old	Caucasian Graduate Degree \$21-60,000/yr	Married 9 years. Carly worked and had just finished graduate school with a degree in counseling before she quit work to stay at home with Ned. Her husband works from home.	Ned has a 6-year-old sister who does not have any health issues. Ned is healthy other than a long standing history of ear infections that requires regular visits to the ear specialists.
Kristy, 28 years old	Marty, 3 years old	Caucasian Bachelor Degree \$21-60,000/yr	Married 5 years. Her husband is 20 years older than she is. Kristy is currently enrolled in nursing school. She was adopted at birth.	Marty has a 6-year-old brother who has Down's syndrome. Additionally, Marty was going to have a baby brother about a year ago, but the baby was miscarried due to multiple birth defects.
Marta, 37 years old	Leon, 4 years old	Caucasian Graduate Degree \$21-60,000/yr	Married 6 years. She works part time in law enforcement. She is planning to go to nursing school.	Leon has a 2-year-old sister who is typically developing. He has no other medical concerns.
Nancy, 40 years old	Frank, 5 years old	Hispanic Graduate Degree >\$100,000/yr	Married 11 years. She moved here from another country 3 years ago. Nancy worked full time prior to moving to the U.S. Currently, the family is contemplating a move to Florida.	Frank is an only child. He moved to the US just prior to his diagnosis with ASD.
Jane, 39 years old	Tim, 3 years old	Caucasian Bachelor Degree >\$100,000/yr	Married 5 years. Jane continues to work full time. The family recently moved from the city in order to find a better school district for their children.	Tim has a 2 year old sister who is typically developing. He has no other medical concerns.

Mother	Child	Demographic Information	Family Information	Child Information
V, 34 years old	K, 3years old	African American Associate Degree \$21-60,000/yr	Married 8 years. Works full time.	K has a 5-year-old brother that is typically developing.
N, 38 years old	H, 3 years old	Caucasian High School/GED \$21-60,000/ yr	Married 3 years. Stays at home and babysits her nephew.	H is an only child. He is seen by ENT for frequent ear infections and also by the Gastroenterologist. He is frequently with his 4-year-old cousin.

Appendix H

Achenbach Child Behavior Checklist Scores of DSM-oriented Scales for Boys and Girls

*Note: Scores for normal, boarder-line, and clinical ranges vary by category. Therefore, the numeric score will be noted along with the range it falls into.

	Affective Problems	Anxiety Problems	Pervasive Developmental Problems	Attention Deficit/Hyperactivity Problems	Oppositional Defiant Problems
Normal Range	0-5	0-7	0-6	0-9	0-7
Borderline Range	6	8	7-8	10	8
Clinical Range	7-20	9-20	9-26	11-12	9-12
Mother/Child Name					
Mary/David	7 Clinical	11 Clinical	15 Clinical	11 Clinical	9 Clinical
Marie/Mark	5 Normal	7 Normal	8 Borderline	0-3 Normal	0-2 Normal
Lucy/Derek	2 Normal	0-2 Normal	10 Clinical	5 Normal	5 Normal
Carrie/Henry	5 Normal	0-2 Normal	13 Clinical	5 Clinical	4 Normal
Carly/Ned	7 Clinical	9 Clinical	14 Clinical	9 Normal	4 Normal

Mother/Child Name	Affective Problems	Anxiety Problems	Pervasive Developmental Problems	Attention Deficit/Hyperactivity Problems	Oppositional Defiant Problems
Kristy/Marty	8 Clinical	5 Normal	7 Boarder-Line	12 Clinical	9 Clinical
Marta/ Leon	6 Borderline	4 Normal	11 Clinical	6 Normal	7 Normal
Nancy/ Frank	0 Normal	4 Normal	12 Clinical	8 Normal	0-2 Normal
Jane/ Tim	5 Normal	0-2 Normal	11 Clinical	12 Clinical	0-2 Normal
V/ K	3 Normal	4 Normal	11 Clinical	10 Borderline	5 Normal
N/ H	3 Normal	0-2 Normal	7 Borderline	5 Normal	4 Normal

Appendix I

Achenbach Child Behavior Checklist Scores of Empirically Based Scales
for Boys and Girls

*Note: Scores for normal, boarder-line, and clinical ranges vary by category. Therefore, the numeric score will be noted along with the range it falls into.

Range	Emotionally Reactive I	Anxious/ Depressed II	Somatic Complaint III	Withdrawn IV	Sleep Problem V	Attention Problem VI	Aggressive Behavior VII
Normal	0-5	0-6	0-4	0-4	0-7	0-5	0-20
Borderline	6-8	7-8	5-6	5	8	6	21-24
Clinical	9-18	9-16	7-22	6-16	9-14	7-10	25-38
Mother/Child Name							
Mary/David	4 Clinical	7 Borderline	5 Borderline	10 Clinical	4 Normal	8 Clinical	22 Borderline
Marie/Mark	3 Normal	5 Normal	6 Borderline	5 Borderline	6 Normal	4 Normal	0-8 Normal
Lucy/Derek	3 Normal	0-1 Normal	0-1 Normal	8 Clinical	2 Normal	3 Normal	12 Normal
Carrie/Henry	4 Normal	4 Normal	2 Normal	8 Clinical	0-1 Normal	5 Normal	9-10 Normal
Carly/Ned	8 Borderline	5 Normal	4 Normal	7 Clinical	4 Normal	7 Clinical	21 Borderline

Mother/Child Name	Emotionally Reactive I	Anxious/ Depressed II	Somatic Complaint III	Withdrawn IV	Sleep Problem V	Attention Problem VI	Aggressive Behavior VII
Kristy/Marty	5 Normal	0-1 Normal	2 Normal	5 Borderline	14 Clinical	9 Clinical	26 Clinical
Marta/Leon	5 Normal	2 Normal	4 Normal	5 Borderline	6 Normal	5 Normal	13 Normal
Nancy/Frank	4 Normal	0-1 Normal	5 Borderline	4 Normal	2 Normal	6 Borderline	0-8 Normal
Jane/Tim	2 Normal	0-1 Normal	4 Normal	9 Clinical	0-1 Normal	9 Clinical	12 Normal
V/K	3 Normal	4 Normal	2 Normal	8 Clinical	2 Clinical	7 Clinical	15 Normal
N/H	3 Normal	0-1 Normal	5 Borderline	3 Normal	3 Normal	2 Normal	17 Normal